

**Parent–professional collaboration: implications for  
service delivery to parents of children with learning  
disabilities.**

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2003



## **Declaration**

I hereby declare that the material contained within this thesis is entirely my own work and has not been submitted towards any other degree or professional qualification.

Date: .....3.11.03.....

## **Acknowledgements**

Thank you to all parents and professionals that took the time to complete questionnaires and participate in the study, to Tracey Watson, Community Nurse, Dr Chris Steer, Consultant Paediatrician, and Nethertown Practice General Practitioners, for giving me permission to use their caseloads for access to parents of children with learning disabilities. Thanks also to Jessie Roberts of PAMIS and Linda Jenkins of Fife Action on Autism for helping in recruitment of participants through their organisations. Many thanks to Arthur Still, Statistician, for his patience and advice, and to Dr Marie Renaud, Head of Learning Disabilities Clinical Psychology Department, for her time, help and support in supervising this thesis. Thank you to Ann Green, NHS Course Manager, for her advice and support. Thank you to my Mum and Dad and to Sarah Quayle, my fiancée, for their love and encouragement. Finally many thanks to Ken Laidlaw, my Academic Supervisor, for his valuable time, guidance, advice, patience and good humour throughout his supervision of this thesis.

## **Abstract**

This study examined the relationship between parents of children with learning disabilities and healthcare professionals providing services to them. Parents were asked to name the most and least helpful professional they had experienced contact with in relation to their child with learning disabilities and rate them using an adapted version of the Helping Behaviour Checklist (HBCL-A) (Cournoyer and Johnson, 1991). An adapted version of the Providers Beliefs About Parents Questionnaire (PBAP-A) (Johnson et al, 1994) measured the degree to which professionals endorsed a collaborative approach towards working with parents of children with learning disabilities across blame, inform, validate and instruct factors. The extent to which these professionals' beliefs on the PBAP-A influenced parents choice of most and least helpful professional was examined. Further analyses investigated whether other characteristics of professionals or characteristics of the family influenced parents choice and rating on the HBCL-A of most and least helpful professionals. Parents choice of the most and least helpful professional was not found to be influenced by professionals' beliefs on the PBAP-A. Parents were more likely to name the professional as most helpful than least if they understood their role, had a larger number of contacts and ongoing contact with them, and had a greater degree of congruence with professionals' beliefs on the instruct factor of the PBAP-A. HBCL-A ratings of most helpful professionals were correlated with parents' age and factors concerning parental stress, support and child's behaviour. HBCL-A ratings of least helpful professionals were correlated with parents' beliefs about parents on the validate factor. Implications for service provision were discussed.



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# **Introduction**

# Introduction

Giving birth to a child with a learning disability is often an unexpected shock for parents. It will inevitably bring parents together with professionals keen to help them through the initial traumatic period and beyond. Historically, professional help was focused predominantly on the well being of the child. Parents were left largely unsupported and received little help from professionals (Mittler and Mittler, 1983). However, the voicing of parents' dissatisfaction with these services (Seligman and Darling, 1997) and the recognition of both their rights and responsibilities with respect to what happens to their child, and of research evidence demonstrating the major influence of parents and families on the child's development (e.g. Wasserman and Allen, 1985), has contributed to the development of legislation, e.g. The Children's Act 1989, (Department of Health (DoH), 1991) and formation of social policy, e.g. the White Papers: *Caring for People: Community Care in the Next Decade and Beyond* (DoH, 1989), *The same as you? A review of services for people with learning disabilities* (Scottish Executive Health Department (SEHD), 2000), that emphasised the importance of the input of parents/carers and their children in the process of planning and implementing appropriate services for their needs. Legislation now states that for intervention to be effective it must take into account the 'whole lifestyle' of the child, along with their family background and culture (DoH, 1991).

This emphasis on working with the whole family indicates the shift in the ideology and practice of helping professions towards a workable collaborative relationship, or

partnership, between parents and professionals (Avdi, Griffin and Brough, 2000). In the area of learning disabilities, this ideological shift has been part of the development of community based, family-centred interventions (Cunningham and Davis, 1985).

Dunst, Trivette and Deal (1994a) outlined a family centred assessment and intervention model as a way of working with the whole family of a child with learning disabilities. As can be seen in figure 1, family needs and aspirations, family strengths and capabilities (family functioning style), and social supports and resources are seen as separate but interdependent parts of the family-centred assessment and intervention process. Help-giving behaviours are central to ensure the smooth running of the model. Dunst et al (1994a) indicated:

The help-giving behaviours used by professionals are seen as the ways in which families are enabled and empowered to acquire and use competencies to procure support and mobilize resources for meeting needs (Dunst et al, 1994a, p.8).

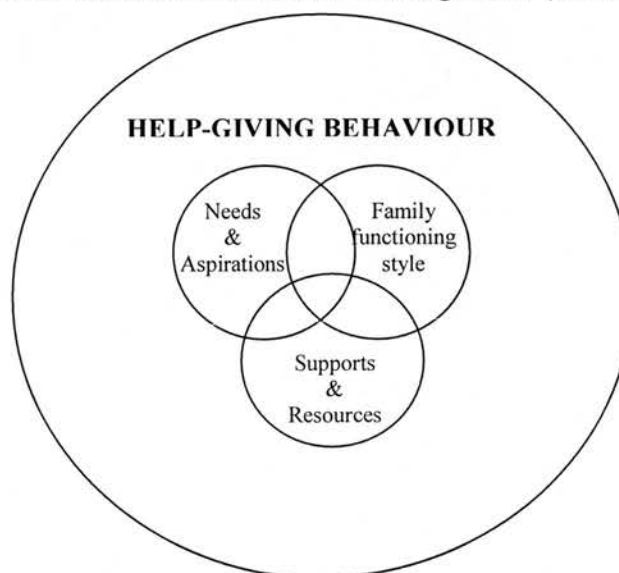


Figure 1: Four Major Components of the Family-Centred assessment and Intervention Model (Dunst et al, 1994a, p.8)



Dunst et al (1994a) suggested that professionals must perfect the necessary skills to work effectively with families in a way that promotes a family's ability to mobilise supports and resources to meet needs and attain aspirations in ways that are both enabling and empowering. These skills involve working collaboratively and in partnership with families.

The first part of this review examines what characteristics are required of professionals to allow partnership to exist with families of children with a learning disability. The current research aims to investigate aspects of the present state of partnership practice of professionals including the extent to which the philosophy of collaboration is reflected in professionals' beliefs and the degree to which these beliefs influence parents' perceptions of the helpfulness of professionals. This review goes on to consider factors that may limit partnership before critically examining research that has investigated how much professionals appear to have taken on board partnership characteristics. The specific aims and hypotheses of the present study are then outlined.

## **CHARACTERISTICS OF PARTNERSHIP**

The recent Scottish Executive Health Department (SEHD, 2003) white paper *Partnership for Care* emphasised the need for a health service where there is:

partnership between clinicians, professionals, patients and carers in understanding a person's condition and making decisions about the right treatment and care. (SEHD 2003, p.19).

Health organisations and staff will be required to have a high level of communication skills and an awareness of the diverse needs of patients (SEHD, 2003). The new

training organisation *NHS Education for Scotland* is to prioritise the provision of training in communication and involvement skills. The aim is for the principles of a patient-focused approach to be built into induction programmes; pre-qualification professional training; continuous personal development and professional training; and leadership development (SEHD, 2003).

Despite the widespread endorsement within legislation of partnership, Dale (1996) and Dunst, Trivette and Johanson (1994b) reported there to be no operational definition of parent-professional partnership. Dale (1996) stated that partnership occurs when there is collaboration on the same project or issue. Dunst and Paget (1991) defined a parent-professional partnership as:

An association between a family and one or more professionals who function collaboratively using agreed upon roles in pursuit of a joint interest or common goal. (Dunst and Paget, 1991, p29).

However, there is no universally accepted definition or statement on what might represent the minimum basic requirements of a parent-professional partnership.

Models of partnership have been developed in attempts to provide hypothetical frameworks of how the ideal relationship between parents and professionals should or could work. Table 1 provides an overview of the evolving relationship between parents and professionals. In following the outline of these models it is apparent there has been a shift of perspective from that of the professional giving knowledge and the parent being a passive recipient of information to that of a process of negotiation taking place between parent and professional (Murray, 2000).

Expert model	Transplant model	Consumer model (Cunningham and Davis, 1985)	Empowerment model (Appleton and Minchom, 1991)	Negotiating model (Dale, 1996)
<ul style="list-style-type: none"> <li>▪ <b>Professional:</b> makes judgements, takes control of what needs doing.</li> <li>▪ <b>Parental</b> involvement secondary, limited to providing information when requested and complying with professional advice.</li> </ul>	<ul style="list-style-type: none"> <li>▪ <b>Professionals:</b> transplant their skills and expertise to parents, instruct parents to guide their activity with their child.</li> <li>▪ <b>Parent:</b> gives feedback on the intervention, but professional preserves similar powers to that of the expert.</li> </ul>	<ul style="list-style-type: none"> <li>▪ <b>Parent:</b> given resource power, 'consumer' who has right to select services for child. Credited with expertise distinct from professionals. Right to opt out of services.</li> <li>▪ <b>Professional:</b> guide parents to effective decisions through negotiation and bargaining. Expert, instructor and consultant to parent, provide parent with options and information.</li> <li>▪ Requires professional understanding of parents.</li> </ul>	<ul style="list-style-type: none"> <li>▪ <b>Professional</b> must: take account of each family having unique adaptational style and differing needs, consider what kind of help parent may need to empower them to be a partner, promote parents' sense of control over decisions, be sensitive to parents' rights to get involved in professional services to extent they choose. Combines right of parent as consumer with a recognition on professional side that the family is a system and a social network which impacts on how individual family members cope with children with learning disabilities.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Professional must strive to bridge gap between parent and professional perspectives. May adopt variety of role positions ('expert', 'instructor', 'consultant' or 'facilitator'), but this negotiated with parent.</li> <li>▪ Partners use negotiation and joint decision making and resolve differences of opinion and disagreement, in order to reach some kind of shared perspective or joint decision on issues of mutual concern.</li> </ul>
<p><b>Advantages:</b> Responsibility for intervention taken off parents' shoulders.</p>	<p>Parents become more involved with professionals, increases knowledge and assertiveness. Professionals work with parents.</p>	<p>Each partner recognised as having equivalent expert powers. Aims to give parents' sense of control. Gives parents role in planning and management of services.</p>	<p>Recognises that diversity in parents will affect a parent's ability to take up a position as a partner. Enabling relationship from professional advocated.</p>	<p>Acknowledges partnership may not be possible due to different perspectives. A method of practice that encompasses the diversity and discrepancies between parents and between parents and professionals. Research evidence needed.</p>
<p><b>Disadvantages:</b> Parent and child placed in subordinate powerless position. Reduces control over lives, may reduce personal efficacy, create dependency. Excludes family members who may have a role to play in intervention effectiveness. Expert prescriptions may be inappropriate to family needs.</p>	<p>Ignores differences between families, assumes all parents motivated to use professional expertise. Professional retains power of authority and control over main decisions.</p>	<p>Assumes parents can represent their own and their child's' needs. Parent as 'consumer' may not be realistic due to limited resources and financial constraints which reduce parental 'resource power'.</p>	<p>Model focuses on one form of empowerment, but other forms may also be needed, such as increased legal rights.</p>	

Table 1, Models of relationships between parents and professionals along with their advantages and disadvantages (based on Dale, 1996).

However, these conceptualisations simplify and extract from what is going on in real life by focusing on normative role behaviour and ignoring the individuality of each person and relationship (Dale, 1996). They are based upon experience in practice but there has been little research to evaluate the success of these models of partnership.

Dunst, Trivette, Boyd and Brookfield (1994c) suggested a similar continuum of models to those outlined by Dale (1996). They suggested help-giving practices varied from those that are expert based (professionally-centred, paternalistic) to those that view clients as agents of professionals (direct guidance, parent training models) to those that are empowerment based (promote active client involvement in acquiring knowledge, learning new skills, exercising choices etc, to enhance competencies necessary to solve problems and meet needs). Dunst (1985) suggested that empowering families provides a basis for partnership in parent-professional relationships. Dunst et al (1994c) compared parents' perceptions of help-giving practices received in each of these three manners and consistently found practice showing a presumption towards an empowerment perspective to be deemed to be more effective by parents than professionally-centred practice.

Dunst et al (1994b) attempted to operationally define elements of partnership by categorising characteristics that had been identified as desirable for partnership by parents and professionals. Categorisations were based upon an examination of the characteristics listed which indicated they could be organised into four sets: beliefs, attitudes, communicative style and behavioural actions. Categorisations were

undertaken by four raters using *a priori* operational definitions of the four categories and are outlined in table 2.

Category	Definition	Characteristics
Beliefs	Cognitive attributions about how one should act or ought to behave toward other people.	Trust, mutual respect, honesty, acceptance, mutually supportive, non judgemental, presumed capabilities.
Attitudes	Particular (emotional) feelings about a person, situation or relationship.	Caring, understanding, commitment, empathy, positive stance, humour, confidence.
Communication Style	Methods and approaches for information sharing between partners.	Open communication, active listening, openness, understanding, full disclosure of information, information sharing.
Behavioural Actions	Behaviours that reflect translation of attitudes and beliefs into actions.	Mutual respect, openness, flexibility, understanding, shared responsibility, mutual support, reciprocity, mutual agreement about goals, dependability, equality, humour, problem solving.

Table 2: A categorisation scheme for organising the major characteristics of parent-professional partnerships (Dunst et al, 1994b, p.206).

The methodology employed to identify elements of partnership relied on asking parents and professionals to list desirable characteristics of partnership. This may limit the range of characteristics expressed as responses may be restricted by parents' experiences of working with professionals and by professionals' experience and training. However, these findings did replicate characteristics that have been proposed to be important for partnership (e.g. Dunst and Paget 1991, Vosler-Hunter, 1988).

Dunst et al (1994b) reported that a helping style that incorporates the major characteristics of partnership, in particular involving help-seekers and enhancing competency, has greater positive impact compared to other types of helping acts in which help-seekers passively respond to help-giver advice. Help-giving is likely to create dependencies when professionals take relative control over their help-seekers fates (Merton, Merton and Barber, 1983). Dependency can then lead to a sense of helplessness, hopelessness, depression or a alienation on the part of the help-seeker (Reid, 1984).

### *Summary*

Although there is no universal agreement as to the most effective method of working with parents, findings such as those by Dunst et al (1994b) do appear to reflect a general consensus in the literature regarding the way forward for help-giving practice with families of children with a learning disability. However, there are limitations upon what it is realistically possible to achieve in terms of partnership due to various constraints which will now be discussed.

## **LIMITATIONS TO PARTNERSHIP**

Dale (1996) outlined circumstances under which partnership can break down:

1. If either the parent or professional is unwilling to meet the other and enter into a collaborative relationship. Personal circumstances on either side may reduce the likelihood of cooperation. Chronic stress on either side may contribute to strained relationships.

2. If there is no willingness or ability to make decisions jointly. This may occur if the professional has less resource power than the parent wants.
3. If interests, viewpoints, priorities and values become too opposing and parents and professionals continue to disagree even after attempts have been made to resolve conflict.
4. In circumstances where the initial contract sets limiting parameters to the negotiating relationship (e.g. in child protection cases where a parent fails to meet minimum requirements.)

It would appear important for any investigation into partnership practice to measure variables that may prevent partnership work from occurring, or that at least put strain on the relationship. Based on the above limitations this would mean measuring levels of stress of both parents and professionals; the resource needs of parents and the capacity of the professional to deliver resources; the level of agreement between parents and professionals on interests, viewpoints, priorities and values; and whether there are any limiting parameters to the relationship. Factors that may influence the extent to which parents and professionals are able to participate in partnership are discussed in more detail below.

### **Factors influencing parents' participation in partnership**

Based upon parent accounts, Dale (1996) reported that parents may find it difficult to discuss their personal needs and concerns openly with professionals. Parents may be frightened that if they indicate ways in which they are coping to professionals they will not be given priority for services. Parents may perceive, or have experienced,

professionals giving one-sided information, for example only giving information supporting the authorities' interests. These factors may prevent parents from trusting professionals and from being honest with them. Parental perceptions of the helpfulness of professionals may vary amongst parents depending upon their expectations and previous experiences of service provision (Dale, 1996).

### *Parental stress*

In relation to the measurement of stress, evidence shows (Byrne, Cunningham and Sloper, 1988) that the majority of families adapt well to having a child with a learning disability while some do not. McConachie (1994) developed a stress/coping model that identified the multiple variables that have been found to impact on the adaptation of parents attempting to deal with the stressor of a child with a learning disability. These include: the characteristics of the child with a learning disability; whether the family is experiencing other additional stressors; the resources available to the parents including family, social and professional support as well as utilitarian resources; and the coping style of the parent, including their beliefs, ability to acquire support and cognitive coping strategies.

Within this model the perceptions of parents about professionals' helpfulness form a part of the coping style that along with the availability and utilization of resources, mediate between potential stress factors and psychological well being. Parents' perceptions of professionals may determine whether they make use of appropriate services. It is also possible that parents' perceptions of professionals are influenced by the variables in the model. It is important that investigations into partnership



consider the impact of these factors in order to provide information for services about what might prevent professionals from being able to work collaboratively with parents.

### *Implications for practice*

Professional services can be viewed as potential moderators of distress and professionals need to understand family experiences and reactions in order to give their intervention appropriate context (McConachie, 1991). McConachie (1991) outlined the implications for practice of the risk factors for parental stress that professionals should be aware may impact on the partnership. To briefly summarise, evidence would suggest professionals need to:

- Identify behaviour problems as early as possible and provide advice to parents on behaviour management.
- Recognise the importance of major life events in adding to family strain and be flexible in how services are offered to parents. This may include times of transition for the child.
- Recognise the importance and balance of the mother and father relationship to family cohesion.
- Help to ensure families receive sources of support beyond the immediate family network.
- Recognise the benefits of informal support networks and respect the families preferred sources of support.
- Recognise professionals own potential for imposing stress on families, for example, through a lack of coordination of services.

- Recognise the importance of cognitive coping skills, through identifying parents' usual coping skills and introducing others. Professionals can help families to realise the role that perceptions of events can have in mediating stress reactions and model coping self-statements. Services can be organised to ensure that family members feel competent; solve problems themselves, feel in control of events and exercise choice.

Professionals must undertake a thorough assessment to identify factors that may disrupt partnership. When examining the impact of these variables on the parent-professional relationship a number of points must be considered. Firstly, the developmental nature of the partnership and the stage it is at when drawing conclusions must be born in mind (Walker and Singer, 1993). It is possible that a professional is aware of factors that might limit partnership but be in an early stage of addressing these problems when the partnership is investigated. This may lead to the professional being perceived by parents as unhelpful because the professional has not yet had the chance to be helpful. Secondly, it is possible that the professional has not assessed these factors and has not taken steps to prevent disruption to the relationship. Thirdly, the professional may be aware of factors causing the family stress but not have the resources available to help. Finally, it is possible that these factors contribute to parents not entering into a collaborative relationship and therefore the professional does not get the opportunity to help. Thus any findings that suggest the helpfulness of professionals is related to variables within the stress/coping model cannot assume a direction of causality.

## **Factors influencing professionals' participation in partnership**

Professionals' ability to work in partnership may be influenced by factors that include their organisational context, stress levels and their attitudes and beliefs.

### *Organisational context*

Johnson, Cournoyer and Fisher (1994) suggested that a professional attempting to work collaboratively with a parent must do so within the context of the organisation for which she or he works, which may have particular mandates, procedures, prevailing attitudes, beliefs and norms. In addition, they suggested the professional might be influenced by his own affective state, his previously acquired repertoire of skills and his own set of attitudes and beliefs that he or she brings to the client encounter.

The role and work context of the professional may limit their communication and negotiation. A professional may be instructed by his or her managers to only recommend certain resources to families. This constraint on partnership may be overcome if the professional is honest about their role constraints with parents (Dale, 1996). Professionals may find it difficult to communicate openly with parents if they feel they have nothing to offer parents due to resource scarcity. Dale (1996) indicated that even at these times professionals may be useful to families in identifying their internal resources and strengths that they can draw on to help their situation. The professional may lend their weight towards parents obtaining their needs or empower the family to be proactive in getting help.

### *Professional stress*

Professionals' interactions with parents may be affected by their levels of stress. For example, the anticipation of breaking the news to parents of their child's disability may evoke feelings of anxiety, distress, inadequacy or defensiveness in professionals. They may be uncertain about how to communicate the news, what to say about the child's prognosis, and how to handle the parents' reaction. Some professionals use defensive strategies to reduce their stress levels, such as avoiding breaking the news and asking a colleague to do it, giving the news abruptly, or by communicating in ways that does not give the true picture (Dale, 1996).

Daws (1984) suggested professionals may adopt defensive reactions against discomfort and anxiety, such as avoidance of the parent, detachment and lack of empathy, leading to inappropriate responses. They may be inappropriately cheerful or give false assurances, may selectively attend to or ignore certain cues, and may rush into advice-giving or activity too quickly, stopping some parents from managing their own pain or limiting parents' opportunity to discuss, in a safe environment, their emotional reactions to the news of their child's limitations.

### *Professional attitudes and beliefs*

Johnson et al (1994) suggested that professional attitudes and beliefs may represent some amalgam of cognitions arising from pre-professional socialisation; professional education; and values, beliefs and norms acquired through socialisation by the employing organisation. These attitudes and beliefs may affect the professional's collaborative behaviour. Professionals may make assumptions about what a parent

wants and needs, which prevent them from finding out the true picture (Dale, 1996). Shapiro (1988) indicated that, based on her experience, the average health professional may not be sufficiently aware of how his or her personal attitudes and biases may interact routinely with interactions with the family. She suggested that professionals can be too quick to label pathology in the family due to a lack of understanding of the parents' perspective. Collins and Collins (1990) suggested that professionals' attitudes may translate into behaviours that offend and alienate parents, who then 'resist' or are 'noncompliant'. Interestingly, Padesky (1998) suggested that a professional's own beliefs and biases may also limit outcome in terms of psychotherapy treatment.

Seligman and Darling (1997) suggested professionals who finished their training over ten years ago may have been trained to have negative views towards individuals with disabilities and their families. They point out that early professional literature in this field characterised children with learning disabilities and their parents as deficient. They also suggested that training in a psychoanalytic perspective leads to professionals blaming problems on the psyche of the client rather than on the structure of the social system. When parents are unable to cope their failure is blamed on a supposed neurotic inability to accept the child. They state:

Real, systems based needs for financial aid, help with child care, or medical or educational services tend to be discounted and attributed to parental inadequacy rather than to a lack of societal resources (Seligman and Darling, 1997, p.205).

Seligman and Darling (1997) however do point out that recently more professionals are receiving training in a systems orientated perspective.

Walker and Singer (1993) suggested that to be collaborative professionals must hold particular beliefs about relationships with parents. They suggested these should include beliefs that:

...cooperation increases the likelihood of mutually satisfying outcomes..., professionals can offer a variety of constructive roles to family members..., both parents and professionals have unique knowledge and expertise to bring to collaborative relationships..., both parents and professionals are constrained by the systems in which they live and work... it is important to identify and clarify these constraints as part of their partnership and to either accept or overcome them (Walker and Singer, 1993, p288).

Walker and Singer (1993) based the need for these beliefs on the philosophy of collaborative practice - but did not provide any evidence that professionals that hold these beliefs are collaborative in practice. Based upon an extensive review of the help-giving literature Dunst, Trivette, Davis and Cornwell (1994d) proposed that the help-givers 'pre-helping attitudes and beliefs', their 'help-giving behaviours' and their 'post-helping responses and consequences' contribute to effective help-giving and promote a sense of family empowerment. They hypothesised that these variables are determinants of a help-seekers sense of control and efficacy which in turn exert positive influence on the physical and psychological health outcomes of the person receiving help. Evidence in support of this hypothesis is discussed below (Dunst et al, 1993).

Marteau (1995) reviewed the beliefs and attitudes of health professionals' in general (i.e. not specifically working with children with learning disabilities) that might influence practice. Factors such as the professionals perceived seriousness of an illness and the perceived benefits of treatment were related to professionals' behaviour. Marteau (1995) asserted that professionals' approaches to treatment are

affected by attributions they make in explaining events. Brewin (1984) found that medical students were more willing to consider psychotropic medication an appropriate form of treatment if patients' life-events were attributed to uncontrollable rather than controllable causes. The theory would suggest that professionals who believe parents of children with learning disabilities problems are due to a 'lack of effort' may blame parents for their children with learning disabilities behaviour problems and be less helpful towards them.

Marteau (1995) suggested that staff cognitions influence the health outcomes of patients by determining their choice of treatment, and by influencing patient cognitions and hence patient behaviour. Marteau's (1995) critique of cognitive approaches to health behaviour and health outcomes reported that cognitive models tend to account for small amount of variance in health outcomes. She stated this may be because these valid theories have not been adequately tested or because the theories are, in fact not valid. Marteau (1995) suggested that more controlled intervention studies are required to determine the circumstances in which cognitive changes affect behavioural change. Cartwright (1979) argued that changing beliefs and attitudes is ineffective because cognitions are only *one of the many* proximal determinants of behaviour. A number of additional factors may also influence professionals' behaviour.

Beliefs of parents and professionals about each other are likely to fluctuate in response to salient current or recent interactions. Parents that have recently had a less helpful meeting with a professional may be more critical of that professional than if

they had recently had a positive interaction. Johnson and Renaud (1997) pointed out that recent frustrations with a particularly abusive parent might cause the professional's tendency to blame parents in general to increase temporarily, whilst work with a parent whose behaviour approximated the professionals' own norms with respect to desirable parenting behaviours might cause lower blame scores than usual.

### *Summary*

This review has so far identified various characteristics necessary for working in partnership and factors that might prevent partnership work from being possible. The present study is interested in determining the extent to which the philosophy of working in partnership appears to have been implemented in professional practice and the extent to which professionals' beliefs may influence the way parents perceive their practice. A review was carried out of studies that have included measures of professionals' application of the characteristics identified as important to partnership.

## **REVIEW OF THE LITERATURE**

To date various methods of investigating professional practice and the extent to which they work in partnership have been carried out. Rather than relying on the anecdotal accounts of parents and professionals about their experiences of each other, studies have focused on the perceptions of parents of professional practice, specifically how helpful they are (Byrne, Cunningham and Sloper (1988), Sloper and Turner (1992), Johnson, Cournoyer, Bond and Betsy (1995), King, Rosenbaum and King (1996), Case (2001), Dunst et al (1994c) and Judge (1997)). Research has also



focused on measuring the behaviour and beliefs of professionals themselves (Woodside, Rosenbaum, King and King (2001), Johnson et al (1994), Johnson and Renaud (1997), Johnson, Cournoyer, Fisher, McQuillan, Moriarty, Richert, Stanek, Stockford and Yirigian (2000) and Bailey, Palsha and Simeonsson (1991)). Only one study (Dunst et al, 1993) has investigated the beliefs of both parents and professionals about each other within the same study. The findings from these studies along with their implications are reviewed below in order to gain an understanding of the present state of collaborative practice and influences upon it.

### **Parental Perceptions of Professional Practice**

There would appear to be an absence of consensus over the use of a generic measure of the practice of professional's working with families of children with learning disabilities. Findings from the few studies that have investigated parents' perceptions of professionals' practice have revealed mixed results concerning professionals' helpfulness.

Byrne, Cunningham and Sloper (1988) investigated how services could meet the needs of families by asking mothers of children with Down's syndrome how helpful they found professionals to be from various different disciplines. They found that 23 per cent of families were in contact with five or more helpful professionals, 56 per cent were in contact with between 2 to 5 helpful professionals, 14 per cent were in contact with 1 helpful professional whilst 6 per cent were not in contact with any helpful professionals. 48 per cent of mothers reported themselves to be completely satisfied with all of the services they received. However, 52 per cent were not

completely satisfied and felt that they had at least some needs that were not being met. Mothers reported that satisfactory service providers showed positive and optimistic attitudes to their children; met their needs and their children's needs; involved parents and treated them as competent; and liaised effectively with other services.

Byrne et al (1988) indicated that the criteria used by mothers to rate perceptions of helpfulness of professionals varied according to parental need and based on parental perceptions of the role of the professional. Byrne et al (1988) concluded that different disciplines were rated according to how much the parent felt they needed contact with them and that parents appeared to judge the helpfulness of different disciplines based upon what they expected them to do. Thus, if a professional 'delivered' what a parent expected they were perceived to be more helpful. This perception could theoretically conflict with professionals' perceptions of appropriate levels of intervention, and may create a tension in the development of a collaborative parent-professional relationship. No measure of the accuracy of parents' understanding of different professionals' role was taken. This may be an area which professionals need to communicate more clearly.

The above findings were a part of a wider investigation into families and their children with Down's syndrome (Byrne et al, 1988). Other findings indicated that between a quarter and a half of mothers scored above cut-off points for depression and distress, and that factors associated with this were their child's behaviour difficulties, family relationship difficulties and low parental education. Byrne et al

(1988) did not investigate the influence of these factors on how parents perceive professionals. As discussed above it is possible that these factors may influence how parents perceive professionals in addition to the behaviour of the professional. No measures were taken of the professionals being rated to validate parents' ratings of them.

The study's use of a Likert scale of helpfulness allowed a wide range of professionals to be quickly given an overall rating of helpfulness. This did not allow for an evaluation of parents' perceptions of the actual behaviours of professionals that might contribute to their helpfulness. Byrne et al (1988) explored what determined mothers answers by asking what they found particularly helpful and unhelpful about the service provided. This provided a useful insight into what parents considered to be important elements of professional helpfulness. One problem with this methodology was that interviews with parents were carried out by investigators themselves which may have led to bias in interpretation of responses. The researchers in this study were also offering intervention to parents. It is possible that this intervention served as a protective factor for families and influenced their responses. Despite this, the relationship between the researchers and the parents may have aided the research if it made parents more revealing in what they reported. Finally, the generalisability of the findings of this study to the area of learning disabilities is restricted as it was limited to only asking mothers of children with Down's syndrome below the age of 11.

Sloper and Turner (1992) investigated parents' views of service contacts and their need for help in a sample of 107 families of young children with severe physical disability of which nearly half also had a learning disability. The study also looked at the contribution of a number of child and family characteristics and resources to the variance in perceived need.

They found that the majority of parents rated professionals as 'very' or 'fairly' helpful, 13 per cent of professionals were rated as being 'a little' helpful whilst 8 per cent were rated as being 'no help'. 73 per cent of parents reported that characteristics of most helpful professionals included a combination of approachability, openness and honesty, giving information and listening to parents. Further characteristics included sensitivity and empathy (19 per cent); treating both the parent and child as individuals and acknowledging the parents role (16 per cent); expert knowledge (14 per cent) and giving practical help (12 per cent). Over half of parents indicated that the most helpful professionals they had encountered worked as a 'link' person acting as a coordinator of services for parents.

Sloper and Turner (1992) reported a significant negative relationship between perceived helpfulness of services and parents' perceptions of unmet needs. This might suggest that parents' perceptions of helpfulness reflect the extent to which their needs are being met, or as causality cannot be assumed - that needs not being met reflect the poor helpfulness of the professional.

Sloper and Turner (1992) found that 40 per cent of variance in unmet needs scores were associated with high levels of strain from life events in the past year, the child having a learning disability in addition to a physical disability, fathers' unemployment and high use of passive optimism by mothers as a coping strategy. Unfortunately perceptions of helpfulness were not analysed in relation to child and family characteristics. Given the relationship between perceptions of need and of helpfulness, it is possible that perceptions of helpfulness might themselves be determined by the variables that influence perceptions of need.

*Overall* perceptions of helpfulness were not related to the total amount of contact parents had with services. Parents did not indicate any particular discipline to be the most helpful to them. The particular personality of a worker and the relationship formed with the family seemed to be more important than professional background (Sloper and Turner, 1992).

The methodology in this study suffered from similar limitations to Byrne et al (1988) in that it relied on a Likert scale and parental accounts with no objective measure of professionals' practice. Measures were taken within two years of the child being diagnosed or within two years of the child starting school. These are both potentially stressful times for parents which may influence their perceptions of the helpfulness of professionals. As noted above, there was no examination of the impact of stress, or any other variables, on parents' perceptions.

Based on a homogenous sample of 84 parents of children with a variety of learning disabilities, Case (2001) reported that negative interaction with professionals is no longer inevitable. Findings indicated that conflict between parents with professionals over service provision was prevalent and professionals often failed to ensure parents had all the information they need. However, professionals were viewed as: approachable, taking parents' needs and concerns into account, taking action accordingly and not making parents feel responsible for their child's disability. Professionals' advice was useful and clear but needed to be requested rather than given.

Case (2001) concluded that an increasingly equitable parent-professional relationship was emerging. He used theoretical levels of partnership (as outlined by Dale (1996) and summarised in table 1, see page 15) to judge the results of parents' perceptions. He suggested that his findings reflect a shift from the role of the professional as expert towards the 'negotiation model' of partnership (Dale, 1996) with the parent-professional relationship presently reflecting the 'consumer model' (Cunningham and Davis, 1985) of partnership as parents appear to possess the rights to contribute to care plans and services. This would suggest professionals can still improve their practice to include characteristics of the negotiation model, such as enhancing the two-way dialogue, underpinned by negotiation and active listening.

Case's (2001) use of models of partnership is appealing as a method of judging the level of partnership reached by professionals and the standard that they need to aspire. However, there is no recognised measure of the type of partnership being

engaged in between parents and professionals. Case (2001) drew his conclusions based on subjective interpretations of his findings.

The measure used in this study was designed by a parental advocacy group - which may mean the measure reflects those particular parents' ideological view and therefore limit the validity of the measure for assessing the concerns of parents of children with learning disabilities in general. In addition, Case (2001) did not measure the practice of professionals to validate his findings nor were the influence of child and parent characteristics upon parent perceptions considered.

King, Rosenbaum and King (1996) developed a measure of parents' perceptions of the process of care-giving in order to assess the 'family centredness' of services defined as:

a style of collaborative care giving in which families work in partnership with service providers (Woodside et al, 2001).

The Measure of Process of Care (MPOC) measures parents' perceptions of the extent to which services they receive engage in: 'enabling and partnership'; 'providing general information'; 'providing specific information about the child'; 'coordinated and comprehensive care for child and family' and 'respectful and supportive care'. The measure asked parents to rate the service as a whole instead of individual professionals. They generally found parents perceived services to 'sometimes' demonstrate the qualities identified by each factor but not to 'a great extent'. This would suggest there is room for improvement in the process of care given to parents by professionals.

King et al (1996) examined the relationship between scores on their Measure of Process of Care (MPOC) and parents' judgement of their level of stress specifically regarding dealing with the service with which they were engaged. They found negative correlations between MPOC scores and parents' perceptions of stress indicating stress was higher when parents were less satisfied with services received. The variation in MPOC scores across other family characteristics was not measured.

The method of asking parents to rate a service as a whole has the advantage of giving an indication as to how the service in general may improve its practice. However, it can not account for the individual variability in the service. For example, parents may have had some positive and some negative experiences of professionals in a service but this may not be reflected in an overall rating. The finding that parental stress about services is negatively related to their perception of the family centredness of the service, does not permit an analysis of whether stress increases specifically due to parents' experience of one professional within the service or due to problems with the whole service. It is also important to remember when considering the relationship between parents' perceptions of professionals and parental characteristics, that professionals are not individually responsible for services to parents and that it may be that parents' experience of professional services as a whole play a more important role in the variance in parents' characteristics than individual professionals.

Dunst et al (1994c) compared parents' perceptions of the helpfulness of professionals using the Professional Helpers Characteristics Scale (HCS) (Trivette and Dunst,



1990) and parents' self efficacy appraisals across three types of services programmes. These were programmes guided by an empowerment philosophy, a direct guidance philosophy or a professional-as-expert philosophy. Data from three different studies were gathered for analysis giving a sample of 1358 parents (mostly mothers).

Studies one and two found staff on programmes adhering to an empowerment philosophy significantly more effective (75 per cent and 79 per cent effective) than staff adhering to direct guidance models (45 per cent and 61 per cent effective) who in turn were more effective than staff using the expert model (25 per cent and 21 per cent effective). In study 3 the same differences were found but to lower percentage of professionals in the direct guidance/empowerment model group being effective (55 per cent). Dunst et al (1994c) suggested this was due to the programme having less of an empowerment philosophy than those in studies one and two. In each study the more effective professionals were found to be, the higher degree of control parents indicated they experienced. Findings suggested that unless professionals employ help-giving practices that actively involve families, the chances of having a positive effect on those families will be diminished.

Whilst professionals guided by an empowerment philosophy were most effective, ratings did suggest there was room for improvement in their practice. An important problem with the methodology of this study, is that it did not make clear how parents chose the target help-giver that they rated. Individual professionals within a programme may interact with parents in different ways and hold different beliefs

about working with parents, so the choice of help-giver rated and how the choice was made is important information. Parents' evaluation of effectiveness does not necessarily represent the philosophy of the programme but may be more indicative of characteristics or the values of the professional rated. No measure was taken of the professional rated to validate parents' ratings of them and the study did not examine the influence of other variables on parents' ratings.

A similar study by Judge (1997) did consider sources of variation in parents' assessment of help-giving practices and perceived control appraisals. Judge (1997) examined whether the location of service provision (home-based or centre-based) and the service group (birth-to-3 year olds or 3-to-6 year olds) would influence help-giving practices and parental control appraisals. Results showed that parent and family characteristics were not related to either help-giving practice or perceptions of personal control. Analysis also found that the location of service provision and the service group did not influence parents' perceptions. The child's age did however account for a small but significant amount (8 per cent) of the variance in perceptions of help-giver practices.

Small significant correlations between help-giver practices and service location and service group were found, suggesting that home-based services and services for children aged birth to 3 years use more effective help-giving practices as rated by parents. Judge (1997) suggested that this may be interpreted that help-giving practice may to some extent be dictated by the opportunities afforded by the setting. Home-based settings may afford greater opportunities for professionals to employ help-

giving behaviours that enable and empower parents. Centre-based settings may influence the roles and responsibilities assumed by professionals in a way that undermines the families' sense of competence. Judge (1997) stated that these findings indicate a need to consider programme characteristics as part of efforts to understand parents' assessment of help-giving. Caution must be taken in interpreting these findings as the correlations among variables were low.

Due to the families in the above two studies being involved at the early intervention stage they may at the time have only recently become involved with early intervention services. This was reported to be the case by Judge (1997). As a consequence satisfaction reported about the way in which a target help-giver interacted with them may be part of a 'honeymoon period' in which families are so appreciative of services provided by professionals that any type of help is assessed as effective. Again, no measures of the characteristics of professionals or their actual practice were taken.

Simpson and Hyland (2003) assessed the experiences of services of parents of children with autistic spectrum disorder in Fife. Semi-structured interviews and a self-complete questionnaire were used to gather information on a sample of 84 parents. More than half of parents (59 per cent) said they received either very little or no helpful information at diagnosis. Some parents reported having a lack of understanding of the roles of different professionals. Over half of the respondents felt that their needs were not being met. These findings indicate areas within which improvements need to be made to services provided to parents. No direct measure

was made regarding the helpfulness of individual professionals but findings would suggest improvements that professionals could take on board such as providing more information and explaining their roles more clearly. The review reported that a general comment made about health services by one parent summed up the views of many:

In general the healthcare professionals we have had contact with are very efficient and caring – however the organization and structure leave a lot to be desired. There are consistently long waiting times for referrals and reviews, there is no set path to follow and there seems to be inadequate dialogue between the different professionals involved in the child's care. (Simpson and Hyland, 2003).

Thus the organisation of the service may be more responsible for short falls than the practice of healthcare staff. This study did not consider whether parents' views varied based on the severity of their child's autistic spectrum disorder or due to parental characteristics. No direct measurement was made of services provided though it was indicated that parents did not have access to a clear multi-agency framework for service delivery.

Cournoyer and Johnson (1991) and Johnson et al (1995) asked parents to rate their experience of the most helpful, least helpful or only professional helping them in relation to problems manifested by their child using the Helping Behaviour Checklist (HBCL). This contained 31 statements regarding helping characteristics a professional might engage in.

Johnson et al (1995) found that behaviours and attitudes that parents want from professionals include honesty; a non blaming attitude; information sharing and acknowledgement of the professionals' own uncertainties; willingness to learn from

parents; and a desire for professionals to view parents as collaborators. Cournoyer and Johnson (1991) suggested that professionals need to improve their practice in relation to giving parents information; explaining how the parent could help the child; involving parents in decision making; valuing parents' opinions; respecting parents' expertise about the child; and helping parents find other services when unable to help. Findings were relevant across mental health practice generally rather than being specific to a particular professional discipline, type of child problem, duration of treatment, number of visits or gender.

In order to examine the discriminant validity of the HBCL, Cournoyer and Johnson (1991) examined the extent to which parents' ratings of professionals were influenced by frustrated parental goals for the child and parents' global satisfaction with their child's progress since treatment began. Parents' ratings of professionals were *not* strongly influenced by frustrated parental goals for the child. However, they did find that parents' global satisfaction with their child's progress since treatment began correlated significantly with many *HBCL* items. Parents who felt more positively about helper behaviour also tended to feel positive about their child's overall progress. It was therefore unclear whether parents' perceptions were accurate reflections of the actual behaviours of the professionals.

Asking parents to rate the most and least helpful professional has the advantage of exploring the range of professional helping behaviour experienced by parents. In addition focusing on a particular professionals' helpfulness allows for a specific insight into the parent's experience of the behaviour of that professional and into

how that particular professional needs to change. However, with no measure of the professionals themselves, the validity of the findings must be questioned as other factors may determine parents' perceptions such as their perception of their child's overall progress or other parental or child characteristics.

#### *Summary of parents' perceptions of professionals*

In summary, research into parents' perceptions of professionals' behaviour is limited and has a number of methodological flaws. The review has found short falls in the helpfulness of professionals based upon parents' perceptions. However, concluding that this means professionals are not collaborative enough may be premature as various factors must be considered that may determine parents' perceptions. In examining the relationship between parents' perceptions and additional variables it is important to recognise that the direction of causality is not clear. Parents' perceptions of professionals may be being influenced by these variables more than by the helpfulness of professionals, alternatively the impact of these variables may be determined by the approach of the professional to the parent.

The studies described relied on parental perceptions of professional behaviour. A measure of professional practice is required in order to corroborate the perceptions of parents. None of the studies attempted to directly measure professional practice itself. The above findings may of course be an accurate reflection of how professionals work with parents but not be a reflection of how professionals want to work with them. Professionals might have beliefs about working with parents that are consistent with collaborative practice but be unable to put these into practice for a

number of reasons outlined above. The present study aims to elucidate whether or not conclusions drawn about professionals' behaviour reflect the beliefs of professionals about working with parents of children with learning disabilities. There have been a limited number of studies exploring the beliefs of professionals about approaches to helping parents. Findings from these studies will now be discussed.

### **The Professionals' Perspective**

To date explorations of the barriers to, and the impact of, recommendations to improve parent-professional partnerships have been limited in scope. As discussed studies have typically been designed to capture and quantify parents but not healthcare professionals' perceptions of services. The benefits of measuring professionals' perspectives include a method of validating findings based upon parents' perspectives and a number of valuable insights for service provision - such as when gaps exist between current and desired health care practices. This can elucidate how to support collaborative practice more effectively (Woodside et al, 2001). Measuring service providers' perceptions may help to gauge the full impact of policy changes and education or training initiatives on professionals.

#### *Professional behaviour*

Woodside et al (2001) attempted to measure the behaviour of professionals within services for children with chronic health conditions from the professionals' perspective. They reported that there was a general absence of broadly focused, valid and reliable self assessment measures of family-centred services for paediatric practitioners and therefore developed the Measure of Process of Care for Service

Providers (MPOC-SP). The measure specifically sought to quantify behaviours rather than the beliefs and attitudes of professionals.

The measure was an adapted version of the MPOC, described above. Professionals were asked the extent to which they had behaved in a family-centred way over the past year on 4 factors: showing interpersonal sensitivity; providing general information; communicating specific information about the child and treating people respectfully. Results from the field test study of the measure on 329 professionals from various disciplines found that professionals put the four factors into practice on average *'to a fairly great extent'*.

As this measure is a self-assessment measure of behaviour, it is a measure of perceived and not observed phenomena. As such the MPOC-SP may not accurately reflect the actual behaviour of professionals. One test of the construct validity of the measure examined the social desirability of responses of participants. 19 participants were randomly selected to complete the measure on a second occasion 3-6 weeks following the first completion, but this time rating what they would consider to be 'ideal' behaviour, rather than how they actually behaved. Results found that 'actual' behaviours were significantly less family centred than what professionals considered to be 'ideal' behaviours. The authors suggested that the measure does therefore validly reflect actual behaviour of professionals.

However, there is a flaw in this measure, as asking professionals the extent to which they engage in these elements of good practice is likely to bias the way in which they



respond. The fact that the sample used to check social desirability indicated that they recognised what 'ideal' behaviour is would suggest it might be unlikely that professionals would indicate that they do not engage in such behaviours to at least some extent. Such a scale is unlikely to capture the range of collaborative professional practice.

In addition, no measure was taken of what prevented professionals from behaving in the 'ideal' way. This may have been due to a number of possible factors including their personal attitudes and beliefs, organisational barriers, or professionals' emotional reaction to the situation. Thus using a measure such as the MPOC-SP alone to identify the extent to which professionals engage in collaborative practice is limited as scores reflect service provision in isolation of all contributing contextual factors.

Woodside et al (2001) suggested the value of using the MPOC-SP in conjunction with the MPOC. This would enable parental and professional perceptions of services to be assessed and contrasted, and provide opportunities to assess the strengths and limitations of family centred practice. They point out that multi-perspective assessment of services could also yield evidence attesting to the validity of the measures. This is a similar idea to that of the present studies use of both parent and professional measures that is discussed further below.

*Professionals' beliefs about working with parents of children with learning disabilities*

In order to investigate whether professionals hold the beliefs and behave in ways attributed to them by parents who completed the HBCL (Cournoyer and Johnson, 1991), Johnson et al (1994) investigated the beliefs of professionals. They hypothesised that behaviours of professionals express the underlying attitudes and beliefs of professionals and that professionals' views of parents might be a critical factor in successfully engaging parents in a collaborative relationship. They suggested professionals' beliefs need to be scrutinised in order to understand the behaviours to which they give rise.

Johnson et al (1994) designed the Provider's Beliefs about Parent's Questionnaire (PBAP) in an attempt to explore whether professionals' beliefs contributed to resistance to collaborative practice with parents.

The PBAP directly measured professionals' beliefs about some of the behaviours parents were asked about in the HBCL (Cournoyer and Johnson, 1991). Many of the PBAP items were written as counterparts to HBCL items. However, there was no one-to-one correspondence between items. The PBAP contains five factors: Blame (parents are to blame for their child's emotional problems), Inform (information should be fully shared), Validate (parents are validated), Medicate (medication is helpful) and Instruct (parents should be instructed how to help their child). Professionals that completed the questionnaire were providers of child mental health related services including learning disabilities services. The measure may therefore

reflect at least in part the views of professionals working with families of children with learning disabilities.

Johnson et al (2000) found one-fifth of professionals sent the *PBAP* were unequivocal in assigning blame to parents for their children's problems. About half the sample showed a mixture of agreement and disagreement with blame items. One third of the sample disagreed with attributions of causality statements. Respondents who agreed with the blame factor: believed that parents were too emotionally involved to report their children's behaviour accurately, had little valuable expertise about their children and did not support open information sharing. This profile resembled that of least helpful professionals reported by parents (Cournoyer and Johnson, 1991).

Based on the premise that the effectiveness of professionals' interventions on behalf of children, particularly the providers skill in collaborating with parents, is influenced by professionals' beliefs about parents and about issues related to work with parents, Johnson et al's (2000) findings suggested that many professionals hold views and engage in behaviours that could impede collaborative practice.

Professionals with low causal attributions showed associated beliefs emphasising sharing information with parents, validating attitudes towards parents, and agreement with instructing parents how to help their children (Johnson et al, 2000). This profile resembled the most helpful workers reported by parents (Cournoyer and Johnson,

1991). Johnson and Renaud (1997) referred to this as a 'parent-friendly' perspective and described this as an empowerment perspective. They stated:

The parent-friendly perspective replaces traditional models of professional experts administering therapy to dysfunctional, disturbed, or pathogenic parents with collaborative, egalitarian problem solving by parents and providers together. (Johnson and Renaud, 1997).

Johnson et al (1997) examined variation in professionals' beliefs across disciplines and concluded that child psychiatrists were most in agreement with parent-friendly beliefs, clinical social workers were least in agreement, with psychologists' midway between the other two groups. Johnson et al (1994) found professionals favouring psychodynamic and family systems theory were significantly more likely to blame parents than those preferring cognitive-behavioural, existential-humanistic or neuropsychological approaches. Cognitive-behavioural professionals were significantly most in favour of information sharing. Those of neuropsychological orientation were most in favour of use of medication, in validating parents and in using instructions to help parents help their children. Johnson et al (1994) suggested these findings reflect the constructs of professionals of different origins.

### **Professionals' Beliefs, Practice and Parent Perceptions**

Dunst et al (1993) included a measure of both professional beliefs and practice and the views of parents about them within the same study. They carried out case study analyses that examined whether or not professional practice was consistent with their beliefs about working with families; their descriptions of their practice; investigator observations of their practice; and family descriptions of their practice.

Twelve professionals were included that worked across 12 different states of America that either implemented family support programs based on family support principles, that ran family support initiatives or that did not implement family support programs at all.

Data was gathered from qualitative interviews with professionals and families. A measure of professionals' agreement with family support principles was also taken and investigators observed professional-family transactions. Findings suggested professionals varied in their consistency in implementing family support principles. Dunst et al (1993) categorised professionals into different helping styles along a continuum from A to E. Three professionals implemented *Helping Style A* which was characterised by beliefs that constituted strong adherence to family support principles, for example one professional described his practice with parents in the following way:

We have an honest and up front relationship. We both feel we have a good partnership. After the family decides what they need, we sit down together and come up with a plan to access the needed resources (Dunst et al, 1993, p.166).

At the other end of the continuum, *Helping Style E*, which was also implemented by three professionals, was mostly inconsistent with family support principles, for example one professional stated:

We tell the parents once a year what we are doing with their son (Dunst et al, 1993, p.171).

Helping Style A professionals agreed most strongly that family support principles reflected their beliefs about working with families on the measure of professional

beliefs, and these beliefs were consistent with their descriptions of their practice and observations of their practice. Helping Style E professionals held a belief system that was mostly inconsistent with family support principles. Dunst et al (1993) suggested these professionals adopted predominantly professional-centred beliefs and practices.

The degree to which professionals' descriptions of their own practice was consistent with practice observed by the investigators and described by parents was examined. Calculations were based on aggregate information available from professionals and from aggregate information available from families, including investigator observations of family-professional transactions. Considerable covariation was found between the descriptors of practice provided by professionals and independently assessed characteristics of the practices based on family descriptions and investigator observations.

Dunst et al (1993) concluded that the more consistent the practices were with family support principles the more family-centred they were and that the agreement between professionals and family/observer descriptions of practice provided corroborative evidence regarding the validity of the findings. This research has considerable merit in that it has included measures of professional beliefs, practice and family ratings of them within the same study. The case study design made it practically possible for investigators to observe professional-family transactions to validate both the families' descriptions of professional practice and the professionals own description of their practice. The relationship between family and professional descriptions of practice also suggest that findings about professionals based upon parents views such

as in studies described above are valid representations of professionals practice. The finding that professionals' reported beliefs were consistent with their practice would suggest the robustness of conclusions about professional practice based upon measures of their beliefs alone.

A number of methodological considerations must be made regarding Dunst et al's (1993) findings. The case study methodology means that a small sample size was used. Replication of the study using a larger sample is necessary to ensure that results can be generalised to a larger population. The method of quantifying family and observer descriptions of professional practice into *degrees of consistency* with family support principles was not clearly explained. This may have been carried out by investigators not blind to the study, thus biasing classification. No indication was given that inter-rater reliability of these classifications was checked. Joining the observer ratings of professional practice with family ratings might bias the family rating. Finally, it would be useful to include an analysis of covariates that may influence the relationship between professional practice and family/observer ratings of professional practice. As no other variables were considered in analysis, it can not be said with certainty that observer/family ratings of professional consistency with family support principles are purely determined by professional beliefs and practice.

#### *Summary of Professionals' Perspective*

Studies examining professionals' self reported behaviours and beliefs reveal that on average professionals do not behave in an 'ideal' manner when interacting with parents as defined by adhering to a family centred approach. There is variation in the

extent to which professionals hold beliefs consistent with working in collaboration with parents. Only Dunst et al (1993) have attempted to measure the impact of professionals' reported behaviours and beliefs on their actual practice and on parents' perceptions of them. No studies described above attempted to measure whether factors such as professionals' affect or years in practice influenced their beliefs or practice.

As there is no agreed single measure or definition of what might represent the minimal basic requirements of a successful parent-professional partnership, an acceptable level of what beliefs or behaviours are 'good enough' has not been established. It is possible that parents will find professionals 'good enough' if parents agree with professionals' beliefs about working with parents. Parents may find professionals to be helpful despite the professional not demonstrating ideal standards of collaboration if the parent has indicated that they do not expect professionals to reach the ideal. No study has attempted to measure whether parents' judgements of professionals are at all related to parents' beliefs about how parents should be treated by professionals. Nor whether parents' judgement of professionals is determined by the extent to which they agree with professionals about their perceptions of parents. The present study included measures to examine the relationship between parents' perception of helpfulness and the congruence between parents and professionals' views about parents.



## CONCLUSION

This review has considered what characteristics and skills are necessary for a professional to engage in a successful collaborative relationship with parents of children with learning disabilities. Whilst further consideration of factors that might limit partnership would appear to be needed across studies, it has been found that there is considerable variation in the extent to which professionals adhere to these characteristics. In order to corroborate the findings in these studies, and therefore support implications for professional practice, it is necessary to measure both parent and professional perspectives within the same study. Johnson et al (1994) and Woodside et al (2001) have developed measures in order to do this but have not carried out the research. One such study has been carried out by Dunst et al (1993) which, whilst having considerable merit, is limited by its small sample size and lack of measures of covariates.

The present study aims to include a measurement of both parent and professional perspectives within the same study. Whilst the direct observation of parent-professional interactions is beyond the scope of the present study, it is hoped that it may provide an insight into the relationship between parents' perceptions of helpfulness and professionals' beliefs about parents of children with learning disabilities, whilst at the same time considering variables that may impose limitations upon the relationship. No other investigation has included all of these measures within one study. This may provide a valuable insight into the accuracy of previous research findings, into the extent to which professionals presently adhere to

collaborative practice, and provide useful information for services keen to develop a collaborative partnership philosophy.

The study used adapted versions of the HBCL (Cournoyer and Johnson, 1991) as a measure of parents' perceptions of professional helpfulness and the PBAP (Johnson et al, 1994) as a measure of professionals' beliefs about parents of children with learning disabilities. Parents were asked to complete the HBCL twice, once whilst considering the most helpful professional and once considering the least helpful professional they have experienced. Parents were asked to complete the adapted version of the PBAP. Measures of family and professional characteristics were also included. The study investigated the following hypotheses.

## **HYPOTHESES**

### **Hypothesis 1: Determining parents' choice of professionals.**

Professionals named as the most helpful professional will endorse collaborative beliefs on the four adapted Professional Beliefs about Parents Scale (PBAP-A) factors significantly more than professionals named as the least helpful. That is:

- **Blame factor (parents are to blame):** Professionals perceived as most helpful will agree less with statements blaming parents for their children's problems than professionals perceived as least helpful.
- **Information factor (information should be fully shared):** Professionals perceived as most helpful will agree more with information sharing statements than professionals perceived as least helpful.

- Validate factor (parents are validated): Professionals perceived as most helpful will agree more with statements validating parents than professionals perceived as least helpful.
- Instruct factor (parents should be instructed how to help their children): Professionals perceived as most helpful will agree more with statements that parents should be instructed how to help their children than professionals perceived as least helpful.

**Hypothesis 2: Congruence between parents and professionals.**

**2a)** Parents and professionals will hold significantly different beliefs about parents of children with learning disabilities. Parents will endorse collaborative beliefs on the four PBAP-A factors significantly more than professionals.

**2b)** The degree of congruence measured by the difference between parents' beliefs (on the Parents BAP-A) and beliefs (on the PBAB-A) of the professionals named as most helpful will be significantly smaller than the degree of congruence measured by the difference between parents' beliefs (on the Parents BAP-A) and beliefs (on the PBAB-A) of the professionals named as least helpful.

# Method

# Method

## PARTICIPANTS

### Parents of children with learning disabilities

Parents of children with learning disabilities were recruited nonrandomly from the Fife clinical psychology learning disabilities department caseload and waiting list (N=112), from the caseloads of a Fife community nurse specialising in children with learning disabilities (N=48), a general practice in Fife (N=11) and a consultant paediatrician (N=10). Two support groups for parents of children with learning disabilities, Profound and Multiple Impairment Service (PAMIS), and Fife Action on Autism, enclosed information about the study in their newsletters, the names of those interested in taking part were passed on to the main investigator and were recruited to the study (N=6). It was originally intended to recruit parents of children with learning disabilities attending special schools in the Fife area in order to enable a wider representation of parents. Unfortunately, the local education authority in Fife declined to give permission for the researcher to approach parents through the local schools. This was due to concerns (outlined in appendix one) that approaching parents through schools may mislead them to think that the study was specifically related to educational services. This restricted the population sampled.

Inclusion criteria included parents whose child with learning disabilities was aged 19 or under. 'Parents' were defined as the principal carers of the child. This could have been the mother or father, or the male or female principal carer. Children were judged to have a learning disability based upon the fact that they were in contact with or had been referred to learning disabilities services, or were in contact with support

groups for parents of children with learning disabilities. No limitations were placed upon the type or severity of the child's learning disability. Parents of children with mild to profound learning disabilities were included as were parents of children with an autistic spectrum disorder.

### **Professionals**

The sampling frames for the study were chosen to ensure that participants were Fife professionals working clinically, though not necessarily exclusively, as learning disability service professionals with children with learning disabilities and their parents.

Names of professionals working with children with learning disabilities within health, education and social services sectors were collected by the researcher. These three sectors were felt to represent areas where qualified professionals would be directly involved with work with children with learning disabilities and their families. Names were obtained from the three community learning disabilities teams operating in Fife and from heads of departments across disciplines. In total a sample of 225 potential professional participants was compiled.

## **PROCEDURE**

### **Parents of children with learning disabilities**

Letters inviting participants to participate in the study (appendix two), along with information about the study (appendix three) and a reply slip (appendix four) with an enclosed stamped addressed envelope for parents to indicate whether or not they would participate was posted to participants. Those participants who indicated a willingness to participate in the study were contacted by phone to arrange a suitable appointment time to complete the 'parent pack' of questionnaires (described below), with the main investigator. Completion of the questionnaires took approximately one hour. This process was time consuming and to ensure reaching all possible participants within limited time constraints some parents were contacted and asked if they would be happy to complete the questionnaires alone by return of post. All parents asked this agreed to complete the questionnaires by post. A cover letter was sent with the postal questionnaire explaining that only one parent was required to complete the questionnaire (appendix five). All participating parents signed consent forms (appendix six). Confidentiality was maintained through use of code numbers.

### **Professionals**

Professionals were either written to or where possible visited within departmental settings and invited to participate in the study through the completion of a brief questionnaire, an adapted version of the Providers' Beliefs About Parents Questionnaire (PBAP-A) (appendix 24) described below. Participants were handed or sent a letter inviting participation (appendix seven), an information sheet about the

study (appendix eight), a consent form (appendix nine), the PBAP-A questionnaire and a stamped addressed reply envelope.

### **Matching**

In order to examine whether parents' perceptions of the helpfulness of professionals was influenced by professionals' beliefs about parents of children with learning disabilities, parents were asked to name the most and least helpful professional they have worked with and rate them on an adapted version of the Helping Behaviour Checklist (HBCL-A, described below), whilst professionals were asked to complete the PBAP-A. To investigate the relationship between parents' responses and the responses of professionals that have worked *directly* with them, data from parents and professionals were matched. To do this both parents and professionals were identified by name in order to match each parent with professionals they had named as most and least helpful. Data recorded included the parents' and the professionals' code number, e.g. parent 12 had contact with professional 37.

### **Ethics**

In order to ensure the study achieved ethical standards for conducting research it was important that participants were able to give their fully informed consent to participate and that participants emerged from the research process unharmed. The study provided information sheets to participants in an attempt to ensure they were fully informed of what the study was about and to reassure them that none participation would not effect service input. It was important that information sheets for this study included information not only regarding the nature of the investigation



into parent-professional relationship, but that made explicit the matching of health care professionals and parents in the process of the study. This included outlining that participants data would be identified by name in order to directly link questionnaires completed by parents with questionnaires completed by professionals they had named as most and least helpful. It was particularly important that this process was clear as participants may feel uncomfortable that their questionnaires would be linked to other participants and choose not to take part. In addition, without being informed of this process parents and professionals working together that had taken part in the study may feel uncomfortable to discover that they had completed questionnaires for the same study without fully understanding how the information they had provided would be used.

Concerns were raised regarding the ethics of the study because the original information sheets (appendix 3 and 8) enclosed to participants did not fully inform them of the matching process. This meant that participants were not in a position to have given fully informed consent and may be vulnerable to feeling discomfort about the fact that they had participated. In order to address this, participants who received the original information sheet were written to (appendix 10 and 11) in order to fully inform them of this matching process and to offer them the opportunity to withdraw their data from the study. Fife Local Research Ethics Committee (LREC) was contacted to inform them of this process and permission was granted to write to participants (appendix 12). In total 1 parent and 13 professionals withdrew from the study.

A new invite letter (appendix 13) and information sheets (appendix 14 and 15) were developed for recruitment of further participants into the study which made the matching process explicit. These were resubmitted to Fife LREC and approval was given for their use (appendix 16).

## **Measures**

A 'parent pack' was developed which included the following battery of questionnaires:

### *Demographic Questionnaire (appendix 17)*

Designed for the study, this questionnaire gathered demographic information about children with learning disabilities and their parents. Parents were asked to indicate their marital status and employment status and their child's age, gender and diagnosis within the demographic questionnaire. This questionnaire also contained questions asking parents to identify the names of professionals they had worked with in connection with their child with learning disabilities. As indicated above parents were asked to identify professionals from health, education and social services sectors. Parents were asked to indicate which professional they found most and least helpful from those named. If they had only worked with one professional they were asked to tick a box indicating 'only'.

### *Helping Behaviour Checklist- Adapted (HBCL-A) (appendix 18).*

Cournoyer and Johnson (1991) developed the Helping Behaviour Checklist (HBCL) (appendix 19) a behaviour rating scale completed by a parent to assess the behaviour

of one mental health professional serving them in relation to their child with mental and emotional disabilities. Johnson et al (1995) indicated that parents' perceptions regarding the quality of service that they receive from professionals have been found to be similar across a range of childhood conditions. This would suggest that findings with the use of their measure might be applied to perceptions of parents of children with learning disabilities. All items are in the form of statements describing behaviours that professional's exhibit. The HBCL was evaluated by 34 experts on professional ethics to establish content validity. Reliability and discriminant validity was established through field testing the questionnaire on 202 parents belonging to support groups. No norms were available for this measure.

The Helping Behaviour Checklist- Adapted (HBCL-A) was an adaptation of the HBCL for use in the present study. It was not necessary to change the wording for parents of children with learning disabilities. However, the HBCL-A was a shortened version of the HBCL. The HBCL contained 31 items. 10 of these items were excluded. These were items 17, 18, 19, 25, 27 which were not considered culturally meaningful. Items 23, 24, 28, 29, 30 were excluded as the HBCL-A was intended to be used for comparison with professionals beliefs and to assess whether professionals and parents views corroborated with each other. These items did not match items, or factors, on the PBAP-A (see below) and were removed.

The original HBCL reported by Cournoyer and Johnson (1991) scored items on a four point scale with parents choosing answers indicating whether the statement about the professional helper was: *almost always true (1), often true (2), seldom true*

(3), or *almost never true* (4). Scoring was reversed for items that indicated negative statements about the professional. However, Cournoyer and Johnson (1991) later adapted the scoring, maintaining the 4 point scale for items 1-16, but asking parents to rate statements on items 17-31 from the choices '*yes, no, or unsure*'. For the purposes of this study the original 4 point method of scoring was maintained for all items, in an adapted format. This adaptation was carried out as the questionnaire gave parents the option to indicate '*don't know*' as an answer to questions. In order to include these answers in total scores the following scoring method was used: almost always true: 0, often true: 1, don't know: 2, seldom true: 3, almost never true: 4. Scoring was reversed for items that indicated negative statements about the professional.

Parents were asked to complete the HBCL-A twice. Once whilst considering the most helpful professional they had had contact with and once whilst considering the least helpful professional they had had contact with. This was an extension of Cournoyer and Johnson's (1991) methodology that asked professionals to rate either the most helpful or the least helpful professional. Additional questions (appendix 20) about the professional being rated were included along with the HBCL-A for both the most and least helpful professionals. This included questions about the discipline of the professional, the length of time the professional had provided services to the family, the number of contacts, whether or not contact was presently ongoing and parents understanding of the professional's role.

The Parenting Stress Index-Short Form (Abiden, 1995), the Aberrant Behaviour Checklist-Community (Aman, Singh, Stewart, Field, 1985), and the Family Support Scale (Dunst, Jenkins, Trivette, 1984) were included in order to examine whether these variables influence parents' perceptions of the helpfulness of professionals.

*Parenting Stress Index-Short Form (PSI)*, (appendix 21), (Abiden, 1995).

The 36 item short form of the PSI was used as an overall measure of parental stress. It was developed according to the concept that the total stress a parent experiences is a function of certain salient child characteristics, parent characteristics, and situations that are directly related to the role of being a parent. It consists of three subscales: parental distress (PD, items 1-12), parent- child dysfunctional interaction (PCDI, items 13-24), difficult child (DC, items 25-36). The parent is asked to indicate level of agreement with a statement on a five point Likert scale (*strongly agree, agree, not sure, disagree, strongly disagree*). The PSI is widely used in research and has the advantage over some other measures of providing established normative data. Normative data is based upon a population of non learning disabled children. Innocenti, Huh and Boyce (1992) compared mothers of children with a variety of disabilities to the PSI normative sample and found that stresses related to parental variables for mothers of children with learning disabilities are similar to those for mothers of normal children whilst parents of children with learning disabilities reported significantly greater stress on the child domain. The PSI short form does not possess a body of independent research that supports its validity. However, Abiden (1995) reports that because it is a direct derivative of the full-length PSI, it is likely that it will share in the validity of the full length PSI.

*Aberrant Behaviour Checklist-Community (ABC)*, (appendix 22), (Aman et al, 1985). This 58 item scale consists of 5-factors: (1) Irritability, Agitation, Crying (items 2, 4, 8, 10, 14, 19, 25, 29, 34, 36, 41, 47, 50, 52, 57); (2) Lethargy, Social Withdrawal (items 3, 5, 12, 16, 20, 23, 26, 30, 32, 37, 40, 42, 43, 53, 55, 58); (3) Stereotypic Behaviour (items 6, 11, 17, 27, 35, 45, 49); (4) Hyperactivity, Non-compliance (items 1, 7, 13, 15, 18, 21, 24, 28, 31, 38, 39, 44, 48, 51, 54, 56); and (5) Inappropriate Speech (items 9, 22, 33, 46). The parent is asked to respond to statements about their child's behaviour through indicating whether the behaviour is: *not at all a problem, a problem but in a slight degree, the problem is moderately serious, the problem is severe in degree*. It has established norms for parent ratings of young people in special education.

*The Family Support Scale (FSS)*, (appendix 23), (Dunst, Jenkins, Trivette, 1984). This measures availability and perceived helpfulness of a variety of sources of support to parents of a child using specialist services. It is designed to study the mediating effects of social support on how parents cope with the demands of bringing up a child with a disability. It includes five subscales for various sources of support: partner/spouse (items 2, 4, 5); informal kinship (items 6, 7, 8, 9, 13), formal kinship (items 1, 3); social organisations (items 10, 11, 12, 17), and professional services (items 14, 15, 16, 18). The parent is asked to rate the perceived helpfulness of support which has been available to the family over the last 3 to 6 months on a 5 point Likert scale. Responses available are: *not helpful at all, sometimes helpful, generally helpful, very helpful, and extremely helpful*. Normative data is available

from a sample of 224 parents (174 mothers and 50 fathers) of children with developmental disabilities or who are at risk for poor developmental outcome.

*Professionals' Beliefs about Parents - Adapted (PBAP-A), (appendix 24).*

The Providers Beliefs about Parents (PBAP, appendix 25), was developed by Johnson et al (1994) to compliment the HBCL in an attempt to assess aspects of the collaborative process in parent-professional relationships. Items were selected based on their prominence in the literature on parent-professional collaboration. It assesses service providers' (i.e. healthcare professionals) beliefs about the role of parents in a child's problems and about what constitutes appropriate behaviour by providers toward parents.

Analysis of the original 33 items completed by 253 American professionals from various disciplines with an average of 11 years of practice, yielded 5 principal components of the measure covering 21 of the items: blame (items 8, 12, 17, 26, 28), inform (2, 22, 25, 29, 31) validate (1, 6, 14, 16, 27, 30) medicate (7, 18, 21) and instruct (3, 20). Six individual questions of the original 33 were eliminated from factor analysis because of low loadings, they were retained by Johnson et al (1994) because of their conceptual importance. Six negatively worded items with low loadings were retained as single items to discourage global response to the predominantly positively worded scale items. These items were not intended to be scored.

The questionnaire was adapted for use with professionals working with children with learning disabilities, this was called the Professionals' Beliefs about Parents-Adapted Scale (PBAP-A), and for use with parents of children with learning disabilities, this was called the Parents Beliefs about Parents Scale (Parents' BAP, appendix 26) and is described below. No norms were available for this measure.

Adaptation involved alteration of wording in items pertaining to children's mental and emotional problems, to wording pertaining to children's learning disability. For example item 1 was altered from: *'Parents of children who need mental health services are usually too emotionally involved to report their children's behaviour accurately'*, to: *'Parents of children who need learning disabilities services are usually too emotionally involved to report their children's behaviour accurately.'*

Various items were removed from the original PBAP questionnaire for use with parents and professionals in the present study. One of these items (item 25) was removed from the 'inform' factor as it was not culturally meaningful. It stated *'Clients should routinely be informed about the costs and payment plans for service.'* Parents would not have to pay for services received from professionals, therefore making this question irrelevant. The six items (items 5, 10, 13, 19, 24 and 32) on the original PBAP, that did not load within any factor of the original PBAP were excluded from this study as it was felt they would contribute little meaningful data. Of the remaining items, six (items 4, 9, 11, 15, 23 and 33 on the original PBAP) were not scored as they were negative items used as respondent checks which Johnson et al (1994) instructed to leave out of analysis.



### *Parents Beliefs about Parents Questionnaire (Parents BAP) (appendix 26)*

This was the same as the PBAP-A with the exception that it was given to parent participants with the title 'Parents Beliefs about Parents Questionnaire'. Following early use of the questionnaire it became clear that parents struggled to answer the three items on the questionnaire from the medication factor (items 7, 18, 21 on the original PBAP). Parents often stated that they were not sure about the use of medication in response to these items. As these questions did not ask specifically about beliefs about parents it was decided that they were not applicable to many parents and that attempts to modify these questions would not change this. They were therefore excluded from further questionnaires.

The PBAP-A and the Parents' BAP scales were scored on a continuum of agreement categories from 1-4 in line with the original PBAP, these being: *strongly agree*, *agree*, *disagree*, *strongly disagree*.

### **Power Analysis**

Based on effect sizes indicated by Johnson et al (2000) in order to achieve sufficient power with a medium effect size, a sample size of N= 64 in each group was required (Cohen, 1992). Calculation was based on detecting a medium difference between two independent sample means, power = 0.8, alpha = 0.05.

# Results

## Results

Data was analysed using the SPSS (v.10) package. Results of evaluation of assumptions led to logarithmic transformation of various variables to reduce skewness and kurtosis, and improve the normality, linearity, and homoscedasticity of residuals. Variables that were transformed are indicated below.

### CHARACTERISTICS OF THE SAMPLE

#### Parents

187 parents were invited to participate in the study and 68 responded. A further 11 respondents indicated they did not wish to participate. 19 parents completed the questionnaires during a home visit with the main investigator, 49 were sent the questionnaire by post, of these 29 completed and returned the questionnaires. In total 46 questionnaires were returned from parents of children with learning disabilities. Family demographics are reported in table 3.

#### *Parenting stress index(PSI)*

Table 4 indicates the mean and standard deviation of PSI scores across subscales. 34 (73.9 per cent) of the 46 participants scored above the clinical cut off point of 90 on the total PSI score. Within the subscales 16 (34.8 per cent) of the 46 parents scored above the high raw score point (defined by Abidin, 1986) for parental distress, 32 (69.6 per cent) of the 46 scored above the high raw score point for parent-child dysfunctional interaction and 34 (73.9 per cent) of the 46 score above the high raw score point on the difficult child subscale.

	N=	%=
<b>Parents</b>	46	100
<b>Mother</b>	43	93.5
<b>Father</b>	2	4.3
<b>Principal female carer</b>	1	2.2
<b>Parent aged 25-35</b>	15	32.6
<b>Parent aged 36- 45</b>	20	43.5
<b>Parent aged 46-55</b>	9	19.6
<b>Parent aged over 55</b>	2	4.3
<b>Parent or partner employed</b>	30	65.2
<b>Parent and partner unemployed</b>	16	34.8
<b>Married or cohabiting with partner</b>	34	73.9
<b>Separated, divorced, widowed or single</b>	12	26.1
<b>Male children</b>	33	71.7
<b>Female children</b>	13	28.3
<b>Child aged 2-5</b>	8	17.4
<b>Child aged 6-9</b>	14	30.4
<b>Child aged 10-14</b>	16	34.8
<b>Child aged 15-19</b>	8	17.4
<b>Child has autistic spectrum disorder</b>	22	47.8
<b>Child has a genetic disorder</b>	11	23.9
<b>Child has an unspecified learning disability</b>	10	21.7
<b>Child has 'other' disability.</b>	3 (2 cerebral palsy and 1 foetal alcohol syndrome)	6.5

Table 3, characteristics of the sample of 46 parent participants and their children with learning disabilities.

<b>PSI score</b>	<b>Mean</b>	<b>Standard deviation</b>
<b>Parent Distress</b>	32.04	11.10
<b>Parent-child dysfunctional interaction</b>	31.00	8.17
<b>Difficult child</b>	41.26	9.09
<b>Total</b>	104.04	24.44

Table 4, mean, standard deviation and range of PSI scores across subscales and total.

### *Family Support Scale (FSS)*

Parents in the sample perceived helpfulness of various sources of support to be lower than the normative sample group (Dunst et al, 1984) of parents of children with developmental disabilities at risk for poor developmental outcome. Table 5 compares total and subscale scores on the FSS with normative data.

<b>FSS Helpfulness rating</b>	<b>Sample Mean</b>	<b>Normative Mean</b>
Spouse/partner	2.26	3.01
Informal kinship	1.70	2.41
Formal kinship	2.32	2.94
Social organisations	1.68	1.88
Professional services	1.93	3.48
Total	1.91	2.69

Table 5, Comparison of total and subscale mean scores on the FSS with normative data. Scores range from 1 to 5.

### *Aberrant Behaviour Checklist*

Log transformations were carried out on irritability, lethargy/withdrawal and stereotype and total scores. Table 6 indicates the mean and standard deviation of ABC scores across the subscales broken down by gender. Normative data is also presented (Brown, Aman and Havercamp, 2002) which is based upon parents'

ratings of young people in special education. Scores fell within one standard deviation of the norms with the exception of males' scores being over one standard deviation above the norms for irritability, lethargy, stereotypic and hyperactivity behaviour. Aman and Singh (1994) indicated that a score of one standard deviation or more above the mean tends to exceed those of about 85 per cent of the population.

	<b>Child's gender</b>	<b>N</b>	<b>Mean</b>	<b>Std. Deviation</b>	<b>Norm</b>	<b>Norm std dev.</b>
<b>Irritability</b>	male	33	18.76	11.18	8.33	7.76
	female	13	7.23	6.11	7.15	8.05
<b>Lethargy</b>	male	33	15.03	9.82	6.45	7.14
	female	13	4.62	3.75	5.76	7.48
<b>Stereotype</b>	male	33	8.27	5.49	2.80	3.39
	female	13	1.92	2.28	1.81	3.25
<b>Hyperactivity</b>	male	33	23.82	12.49	13.06	8.71
	female	13	9.54	8.48	8.71	9.72
<b>Inappropriate speech</b>	male	33	5.30	4.07	2.12	2.63
	female	13	3.00	3.96	1.79	2.59
<b>Total</b>	male	33	71.15	35.16		
	female	13	25.69	17.06		

Table 6, n, mean and standard deviations of ABC scores and comparative norms (Brown et al, 2002).

# **Professionals**

99 professionals returned the PBAP-A. Table 7 indicates the number of professional participants from each discipline along with their predominant orientation.

	Psycho-dynamic	Family systems	Cognitive/ behavioural	Neuro- psychological	Existential/ humanistic/ holistic	Medical	Other	Total
Clinical Psychologist	1	1	5	2	1			10
Assistant Psychologist			4					4
Educational Psychologist		1					3	4
Paediatrician						12		12
Psychiatrist						3		3
Social Worker		5	1			1		7
Occupational Therapist					3			3
Health Visitor	1	22	14		1	2		40
Community Nurse			2			6	1	9
Speech Therapist			1	1		3		5
Physio-therapist						2		2
	2	29	27	3	5	29	4	99

Table 7, Discipline of the professional by professional's predominant orientation.

Table 8 shows the age of participating professionals along with the number of years they have been in practice.

Age	Number of years in practice						
	1-5	6-10	11-15	16-20	21-25	Over 25	Total
20-29	8	3					11
30-39	9	7	3	3			22
40-49	3	16	9	11	9		48
50-59		1	5	4	3	2	15
60-69				1		2	3
	20	27	17	19	12	4	99

Table 8, Age of professionals by their number of years in practice.



**DISCRIMINANT VALIDITY OF MOST HELPFUL AND LEAST HELPFUL CATEGORIES**

In order to examine the discriminant validity between categories of professionals named by parents as either ‘most’ or ‘least’ helpful, comparison was made between parents’ ratings on the HBCL-A of professionals categorised by parents as either most or least helpful.

Log transformations were carried out on the most and least helpful professionals HBCL-A scores. Table 9 indicates pre-transformation mean scores and standard deviations for the most and least helpful professionals rated by parents and overall ratings of helpfulness. Independent sample t-tests, using transformed HBCL-A scores, indicated that these scores significantly differed with each other ( $t = 13.43$ ,  $df = 83$ ,  $p < 0.0005$ , two tailed).

HBCL-A score	N	Mean score	Standard deviation	t	p
Most helpful professionals	46	8.09	6.43	13.43	0.0005
Least helpful professionals	39	43.15	9.08		

Table 9, N, Mean and standard deviation for pre-transformed HBCL-A scores for professionals named by parents as the most and least helpful. Lower scores indicate increased helpfulness, maximum score = 84.

*Summary*

This result suggests that parents make a meaningful distinction when rating ‘most’ verses ‘least’ helpful professionals indicating the discriminant validity of the

categories. This is important as it is empirically possible that a distinction would be difficult to make should parents have perceived a similar level of helpfulness across professionals, such as only helpful or only unhelpful input. This result however indicated that overall this is not the case.

## **HYPOTHESIS 1**

Professionals named as the most helpful professional will endorse collaborative beliefs on the four PBAP-A factors significantly more than professionals named as the least helpful. That is:

- Blame factor (parents are to blame): Professionals perceived as most helpful will agree less with statements blaming parents for their children's problems than professionals perceived as least helpful.
- Information factor (information should be fully shared): Professionals perceived as most helpful will agree more with information sharing statements than professionals perceived as least helpful.
- Validate factor (parents are validated): Professionals perceived as most helpful will agree more with statements validating parents than professionals perceived as least helpful.
- Instruct factor (parents should be instructed how to help their children): Professionals perceived as most helpful will agree more with statements that parents should be instructed how to help their children than professionals perceived as least helpful.

Table 10 indicates the mean score and percentage of level of agreement professionals as a whole (N=99) have with each factor on the PBAP-A.

	Mean	Strongly agree (%)	Agree (%)	Disagree (%)	Strongly disagree (%)
<b>Blame</b>	9.33	0	6.1	62.6	31.3
<b>Inform</b>	7.11	38.4	55.6	6.1	0
<b>Validate</b>	9.87	53.5	45.5	1	0
<b>Instruct</b>	4.02	30.3	38.4	28.3	3

Table 10, The mean score for each factor and the percentage of level of agreement professionals have with each factor on the PBAP-A. N=99, blame scores are out of 20, inform scores out of 16, validate scores out of 24 and help scores out of 8. Lower scores indicate more collaborative beliefs.

The testing of hypothesis 1 required the scores of professionals that had been named by parents as the most or least helpful professional to be available. In total 33 of the professionals identified as the most helpful professional had returned PBAP-A questionnaires and 13 professionals identified as the least helpful had returned questionnaires. However, a number of professionals were named more than once by parents so their score was only included in analysis once. In total 15 *different* professionals were named as the most helpful and 10 *different* professionals as the least helpful. Table 11 indicates the theoretical orientation, years in practice, age and gender of the most and least helpful professionals. Table 12 indicates the number of each discipline reported to be the most and least helpful by parents of children with learning disabilities.

	Most N	Most %	Least N	Least %
<b>Theoretical orientation</b>				
Family systems	1	3	4	30.8
Cognitive/behavioural	5	15.2	5	38.5
Medical	23	69.7	0	0
Other	4	12.1	4	30.8
<b>Years in practice</b>				
1-5	2	6.1	0	0
6-10	6	18.2	2	15.4
11-15	4	12.1	7	53.8
16-20	6	18.2	2	15.4
21 plus	15	45.5	2	15.4
<b>Age</b>				
20-29	2	6.1	0	0
30-39	3	9.1	0	0
40-49	19	57.6	7	53.8
50-59	9	27.3	6	46.2
<b>Gender</b>				
Male	19	57.6	4	30.8
Female	14	42.4	9	69.2

Table 11, The theoretical orientation, years in practice, age and gender of the most and least helpful professionals.

Discipline	MOST	MOST	LEAST	LEAST
	N	%	N	%
Clinical Psychologist	10	21.7	3	7.5
Educational Psychologist	2	4.3	13	32.5
Paediatrician	17	37.0	3	7.5
Psychiatrist	2	4.3	2	5.0
Social Worker	3	6.5	7	17.5
Occupational Therapist	0	0	2	5.0
Health Visitor	3	6.5	7	17.5
Community Nurse	2	4.3	1	2.5
Speech Therapist	7	15.2	2	5.0
<b>Total</b>	<b>46</b>	<b>100.0</b>	<b>40</b>	<b>100.0</b>

Table 12, Number and percentage of each discipline reported to be the most and least helpful by parents of children with learning disabilities.

Table 13 indicates the mean scores and standard deviations for these most and least helpful professionals on each of the PBAP-A factors. Independent sample t-tests found no significant differences between most and least helpful professionals on any factor. The failure to find any significant differences mean that hypothesis 1 can not be accepted.

### Post hoc power test

Due to the small sample size it is possible that a type 2 error may occur when testing hypothesis 1. In order to evaluate these negative results we need an estimate of power. Table 14 indicates the effect size and power obtained by the present test and indicates the sample size required to get a power of 0.80 with this effect size based on Cohen's (1988) sample size tables. As can be seen to achieve a power of 0.80 with these effect sizes would require much larger sample sizes on each factor of the

PBAP-A. It may therefore reasonably be concluded that if there is an effect size it is likely to be very small and perhaps of little importance.

Professionals beliefs about parents factor	Professionals perceived to be most or least helpful.	N	PBAP-A Mean	Std. Dev t	p
Blame	most	15	9.73	2.15	0.18 N.S.
	least	10	9.90	2.38	
Inform	most	15	7.60	1.50	0.66 N.S.
	least	10	7.18	1.40	
Validate	most	15	10.00	2.20	0.34 N.S.
	least	10	10.30	2.28	
Instruct	most	15	3.8	1.01	1.98 N.S.
	least	10	4.70	1.25	

Table 13, mean scores and standard deviations on PBAP-A factors for professionals selected as ‘most’ or ‘least’ helpful by parents. Blame scores are out of 20, inform scores out of 16, validate scores out of 24 and help scores out of 8. Lower scores indicate more collaborative beliefs.

PBAP-A factor	Effect size	Power in this study	N needed per group to obtain power =0.80
Blame	0.001	0.05	>1571
Inform	0.018	0.10	>1571
Validate	0.005	0.06	>1571
Instruct	0.15	0.48	982

Table 14, effect size and power obtained on each factor of the PBAP-A in the study and estimates of N required to obtain power of 0.80.

### *Summary*

Based on the results it would appear that parents decision to identify a professional they have worked with as the most or least helpful is not influenced by the beliefs about parents of the professional they choose. Hypothesis 1 could not therefore be accepted.

### **Post hoc analyses**

Post hoc analyses were carried out to explore whether there may be further determinants of parents' perceptions of professional helpfulness. The Sign test using binomial distribution examined whether parents' choice of most and least helpful professionals varied based upon whether or not they had ongoing contact with the professional they had named and their understanding of the professional's role defined for the purposes of this study as parents answer to the question: 'Was it made clear to you exactly why you were seeing this professional as opposed to a member of a different profession?'.

A significant difference between parents understanding of the role of most and least helpful professionals ( $N - \text{Ties} = 16$ ,  $p < 0.005$ , two tailed) was found. Parents indicated understanding the role of professionals they named as the least helpful but not the role of the most helpful professional 2 times. They indicated understanding the role of the most helpful professional but not the role of the least helpful professional 14 times. The pattern of results is indicated in figure 2: in brief, parents are more likely to name the professional as most helpful if they understand their role.



The Sign test also revealed a significant difference between whether or not parents had ongoing contact with the professional named as the most and least helpful professionals ( $N - \text{Ties} = 19$ ,  $p < 0.05$ , two tailed). Parents had ongoing contact with the least helpful professional but not the most helpful professional 4 times, and had ongoing contact with the most helpful professional but not the least helpful professional 14 times. The pattern of results is indicated in figure 3: in brief, parents are more likely to name the professional as the most helpful if they have ongoing contact with them.

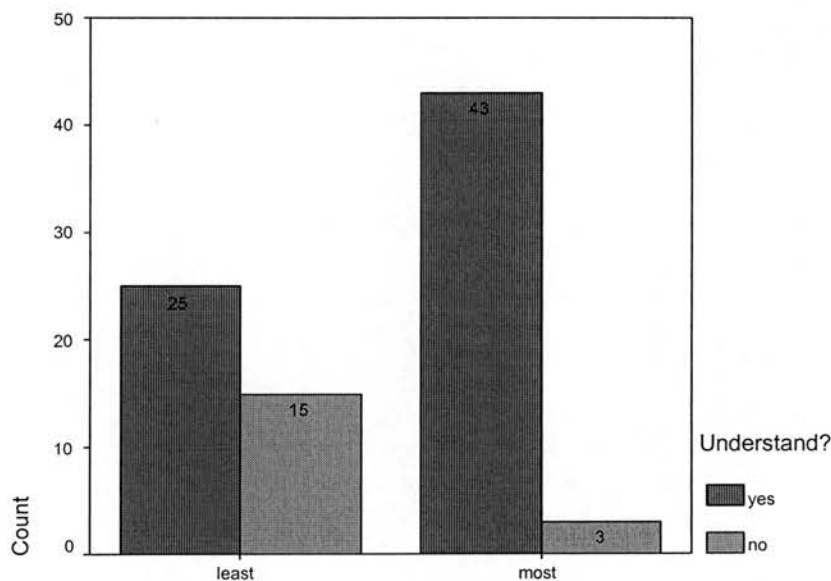


Figure 2, parents' understanding of the role of the professional they had named as either most or least helpful.

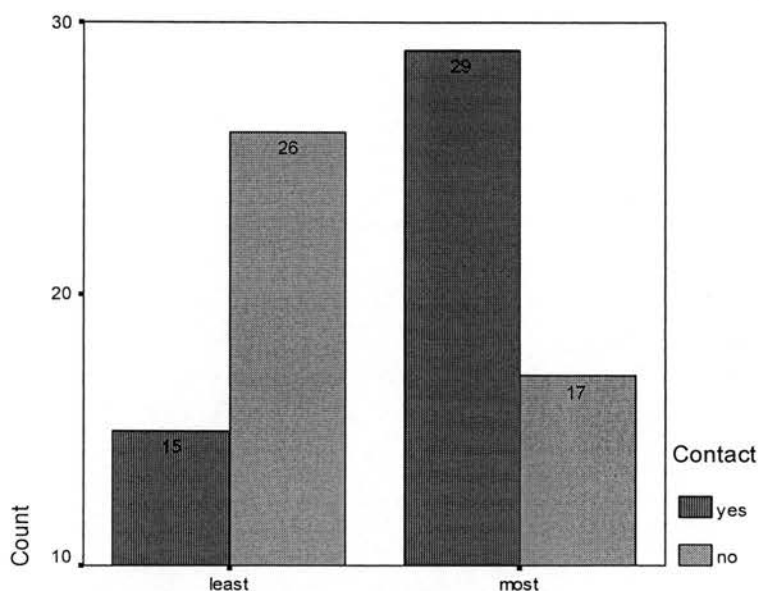
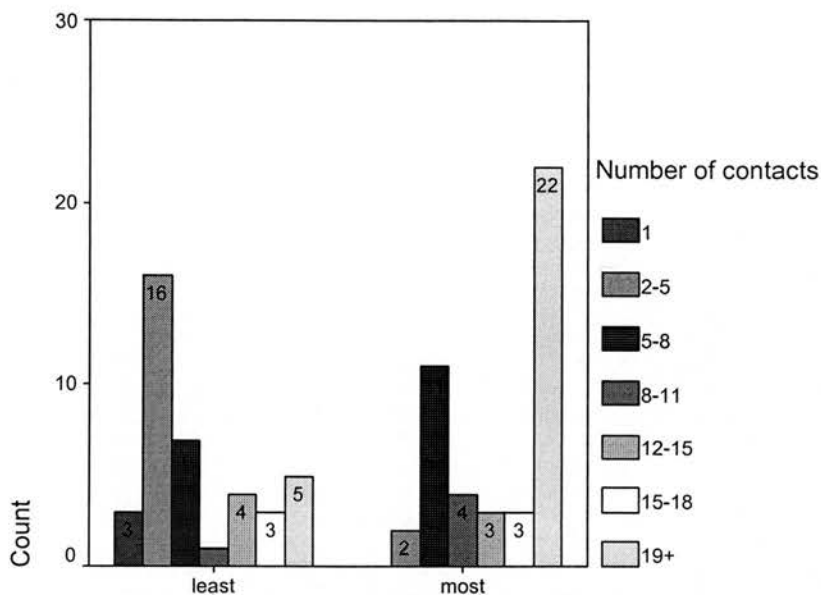


Figure 3, parents' indication as to whether or not contact was ongoing with the professional they had named as either most or least helpful.

Mann-Whitney tests examined whether choice of most and least helpful professional varied according to the frequency and number of contacts parents had with the professional. No significant difference between parents choice of most and least helpful professional across the length of time they were in contact with the professional was found. Significant differences were found between parents choice of most and least helpful professional across number of contacts between the parent and the professional ( $U= 392.00$ ,  $N_1= 39$ ,  $N_2= 45$ ,  $p<0.0005$  two tailed). There were significantly more contacts between parents and most helpful professionals (mean= 12-15 contacts) than parents and least helpful professionals (mean = 5-8 contacts). Figure 4, reports the number of contacts of parents with most and least helpful professionals.



Most and Least helpful professionals.

Figure 4, the number of contacts of parents with most and least helpful professionals.

### Summary

The Sign and Mann-Whitney tests carried out suggest that parents of children with learning disabilities are significantly more likely to name a professional as most helpful rather than least helpful when they understand the professional’s role, have ongoing contact with the professional, and have an increased number of contacts with them.

Further post hoc analysis examined whether parents perceptions of professionals helpfulness on the HBCL-A was influenced by family characteristics (i.e. parent’s age, parent’s marital status, parent’s employment status, parents’ beliefs about parents (on the Parents’ BAP), parent’s level of stress (on the PSI), parent’s level of support (on the FSS), child’s problem behaviours (on the ABC), child’s diagnosis,

child's age, child's gender or professional characteristics (i.e. discipline, years in practice, age, theoretical orientation, gender).

Pearson correlations between HBCL-A scores and family and professional characteristics were carried out separately for most and least helpful professionals. The full correlation matrix is reported in appendix 29. Table 15 reports significant correlations found between HBCL-A scores for most helpful professionals and family characteristics.

#### *Most helpful professionals*

Significant correlations were found between HBCL-A scores for most helpful professionals and parent's age ( $r = -0.36, p < 0.05$ ), parent distress on the PSI ( $r = 0.41, p < 0.01$ ), parent child dysfunctional interaction on the PSI ( $r = 0.33, p < 0.05$ ), total parent stress on the PSI ( $r = 0.36, p < 0.05$ ), informal kinship support on the FSS ( $r = -0.51, p < 0.01$ ), social organisation support on the FSS ( $r = -0.32, P < 0.05$ ), and total support on the FSS ( $r = -0.39, p < 0.05$ ), parents perceptions of their child's lethargy/withdrawal on the ABC ( $r = 0.49, p < 0.01$ ). No significant correlations were found with professionals characteristics.

#### *Least helpful professionals*

Least helpful HBCL-A scores did not significantly correlate with any variables with the exception of a significant negative correlation ( $r = -0.35, p < 0.05$ ) with the validate factor on the parents beliefs about parents scale. No significant correlations were found with professionals characteristics.

Scatter plots comparing significant correlations between HBCL-A scores for most helpful professionals with family characteristics and non significant correlations between HBCL-A scores for least helpful professionals with family characteristics are reported in appendix 27.

### *Summary*

The significant Pearson correlations suggest that HBCL-A scores may vary based upon differences in certain family characteristics rather than based upon the beliefs about parents of the professionals that they are rating.

	Parents rating of helpfulness of the professional named most helpful (HBCL-A).	Parents rating of the kinship support on FSS.	Social organisations support on FSS.	Total support on FSS.	Parent distress score on PSI.	Parent - child dysfunctional interaction score on PSI.	Total score on PSI.	Transformed ABC lethargy/withdrawal factor.	Parent's age
Parents rating of the helpfulness of the professional named most helpful (HBCL-A).	1.000	-.512**	-.322*	-.385**	.410**	.329*	.362*	.49**	-.36*
Informal kinship support on FSS.	-.512**	1.000	.609**	.807**	-.461**	-.391**	-.45**	-.347*	.091
Social organisations support on FSS.	-.322*	.609**	1.000	.772**	-.308*	-.130	-.227	-.26	.040
Total support on FSS.	-.39**	.807**	.772**	1.000	-.336*	-.212	-.27	-.29	-.162
Parent distress score on PSI.	.410**	-.461**	-.308*	-.336*	1.000	.606**	.86**	.32*	.062
Parent - child dysfunctional interaction score on PSI.	.329*	-.391**	-.130	-.212	.606**	1.000	.87**	.52*	-.048
Total score on PSI.	.36*	-.450**	-.227	-.270	.863**	.865**	1.000	.50*	.003
Transformed ABC lethargy/withdrawal factor.	.49**	-.347*	-.256	-.290	.316*	.524**	.50**	1.000	-.010
Parent's age	-.36*	.091	.040	-.162	.062	-.048	.003	-.010	1.000

Table 15, significant correlations of variables with HBCL-A scores for most helpful professionals: \*\* Correlation is significant at the 0.01 level (2-tailed), \* Correlation is significant at the 0.05 level (2-tailed).

Appendix 28 reports further post hoc analysis that examined whether professionals' beliefs on the PBAP-A influenced HBCL-A scores whilst adjusting for family characteristics that have been found to be significantly correlated to the HBCL-A. Briefly, analysis of covariance (ANCOVA) found that even after adjusting for family characteristics no significant effect was found between professionals' beliefs about parents on the PBAP-A and HBCL-A scores for most and least helpful professionals.

**HYPOTHESIS 2A**

Parents and professionals will hold significantly different beliefs about parents of children with learning disabilities. Parents will endorse collaborative beliefs on the four PBAP-A factors significantly more than professionals.

Log transformations were carried out on the inform and instruct factors of both the parents’ beliefs about parents (Parents BAP) and professionals’ beliefs about parents (PBAP-A) scales. Table 16 reports the mean scores for parents and professionals beliefs on each factor. Independent sample t-tests revealed parents and professionals beliefs differ significantly on blame ( $t= 3.63$ ,  $df= 143$ ,  $p=0.0005$ , two tailed), inform ( $t= 5.46$ ,  $df= 143$ ,  $p=0.0005$ , two tailed) and instruct ( $t=2.07$ ,  $df=143$ ,  $p<0.05$ , two tailed) factors.

Beliefs about parents	Parent verses professional beliefs	N	Mean	Std. Dev	t	p
Blame	professionals	99	9.33	2.21	3.63	0.0005
	parents	46	7.85	2.47		
Inform	professionals	99	7.11	1.69	5.46	0.0005
	parents	46	5.57	1.63		
Validate	professionals	99	9.87	2.44	1.17	N.S.
	parents	46	9.37	2.30		
Instruct	professionals	99	4.02	1.34	2.07	0.05
	parents	46	3.52	1.00		

Table 16, mean scores of parents’ and professionals’ beliefs about parents. Blame scores are out of 20, inform scores out of 16, validate scores out of 24 and instruct scores out of 8. Lower scores indicate more collaborative beliefs.



*Summary*

This result indicates that hypothesis 2A can be accepted across blame, inform and instruct factors but not on the validate factor. Parents hold significantly more collaborative beliefs than professionals on blame, inform and instruct factors only.

**HYPOTHESIS 2B**

The degree of congruence measured by the difference between parents’ beliefs (on the Parents BAP-A) and beliefs (on the PBAB-A) of the professionals named as most helpful will be significantly smaller than the degree of congruence measured by the difference between parents’ beliefs (on the Parents BAP-A) and beliefs (on the PBAB-A) of the professionals named as least helpful.

Table 17 indicates the mean differences between parents and professionals beliefs. Independent sample t-tests found no significant difference between the differences in scores on the blame, inform and validate factors. A significant difference was found on the instruct factor ( $t=2.52$ ,  $df= 44$ ,  $p<0.05$ , two tailed).

<b>PBAP-A Factor</b>	Difference between parent and most helpful professional beliefs about parents. (n=33)	Difference between parent and least helpful professional beliefs about parents. (n=13)	<b>t</b>	<b>P value</b>
Blame	2.67	2.92	0.35	N.S.
Inform	2.55	2.54	0.01	N.S.
Validate	2.18	2.38	0.35	N.S.
Instruct	1.24	2.00	2.17	P<0.05

Table 17, Mean differences between parents’ beliefs about parents and most and least helpful professionals’ beliefs about parents.

### *Summary*

This result indicates that parents beliefs about parents did not differ to a greater extent with professionals named as the least helpful compared to professionals named as the most helpful on blame, inform and validate factors. Hypothesis 2B can not therefore be accepted across these factors. However, a significantly higher degree of congruence was found between beliefs of parents and most helpful professionals compared with beliefs of parents and least helpful professionals on the instruct factor. Hypothesis 2B was therefore accepted on this factor.

Parents indicate a mean score of 3.52 on the instruct factor compared to a mean score of 3.53 for professionals named as most helpful and 4.90 for professionals named as least helpful. This suggests that professionals named as most helpful hold beliefs closer to parents beliefs because their beliefs are more collaborative than least helpful professionals.

It was considered of interest to this study to identify whether professionals beliefs about parents on the PBAP-A varied as a result of their characteristics. A post hoc hypothesis was therefore added as indicated below.

### **POST HOC HYPOTHESIS**

Professionals' beliefs as measured by the four PBAP-A factors will vary as a result of their discipline, theoretical orientation, years in practice and age.

Specifically, it is hypothesised that:

- a) professionals will hold less collaborative beliefs on all factors of the PBAP-A if they are medical or nursing staff than professionals that are psychologists, allied healthcare professionals or social workers.
- b) professionals will hold less collaborative beliefs when they work to a medical orientation compared with other orientations and more collaborative beliefs when they indicate they prefer a cognitive-behavioural orientation compared to other orientations, with other approaches falling in between these two orientations.
- c) the older the professional is the less collaborative the professionals' beliefs will be on all four PBAP-A factors.
- d) the more years in practice the less collaborative the professionals' beliefs will be on all four PBAP-A factors.

Log transformations were carried out on the inform and instruct factors of the professionals' beliefs about parents (PBAP-A) scales. The number of years that professionals have been in practice variable remained slightly skewed even after

transformation. Departure was minimal however and the transformed variable was considered robust enough for analysis (Zimmerman and Zumbo, 1993).

Multivariate analysis of variance (MANOVA) was carried out using all four factors of the PBAP-A as the dependent variables. Significant correlations were found between these factors but none exceeded 0.70, therefore analysis was deemed appropriate based on criteria suggested by Brace et al (2003). Each of the independent variables was entered into the MANOVA separately. The small number of participants from some disciplines meant that comparisons of PBAP-A factors were not carried out by discipline, but by professional grouping, as indicated in table 18. The small number of professionals indicating they used psychodynamic, neuropsychological, existential and 'other' theoretical orientations meant that these four orientations were categorised together as 'other orientations', as indicated in table 19.

Results found no significant effects of professional grouping, age or number of years in practice on the combined dependent variable of professional beliefs. A significant effect of the professionals' theoretical orientation on the combined dependent variable of professional beliefs ( $F_{(12, 282)} = 2.37$ ,  $p < 0.05$ ; Wilks' Lambda = 0.75; partial eta squared = 0.09) was found.

Discipline	N for each discipline	Professional grouping	N for professional grouping
Clinical Psychologist	10	Psychologists	18
Assistant Psychologist	4		
Educational Psychologist	4		
Paediatrician	12	Medicine	15
Psychiatrist	3		
Health Visitor	40	Nursing	49
Community Nurse	9		
Occupational Therapist	3	Allied Healthcare Professionals	10
Physiotherapist	2		
Speech Therapist	5		
Social Worker	7	Social work	7
<b>Total</b>	<b>99</b>		<b>99</b>

Table 18, indicates which disciplines were merged to form the professional grouping categories.

Theoretical orientation	N for each theoretical orientation
Family systems	29
Cognitive/behavioural	27
Medical	29
Other orientations (Psychodynamic: n= 2, Neuropsychological: n= 3, Existential: n= 5, Other: n= 4)	14
<b>Total</b>	<b>99</b>

Table 19, theoretical orientations of professionals.

In order to determine which of the four factors of the PBAP-A were contributing to the significant effect of the professionals' theoretical orientation, the univariate

ANOVAs for each of the four PBAP-A factors included in the MANOVA output were examined. In order to avoid a type 1 error a Bonferroni adjusted alpha level was calculated to determine whether or not each ANOVA was significant, as recommended by Brace et al (2003). As there were four dependent variables the alpha level of 0.05 was divided by four, leaving a Bonferroni adjusted alpha level of 0.013. ANOVAs revealed that the theoretical orientation of professionals did not influence professionals beliefs on the PBAP-A blame, inform or instruct factors, but did influence the extent to which they endorsed collaborative beliefs on the validate factor of the PBAP-A ( $F_{(3,95)} = 7.83, p < 0.0005$ ).

Employing the Bonferroni post hoc test, significant differences were revealed between professionals beliefs about parents on the validate factor of the PBAP-A across their preferred theoretical orientation. Mean PBAP-A scores for the validate factor across theoretical orientation are indicated in figure 5. Mean PBAP-A scores on the validate factor were significantly more collaborative for professionals indicating use of 'other orientations' than professionals adhering to a medical orientation ( $p < 0.005$ ). Professionals using cognitive behaviour approaches were also significantly more collaborative than professionals adhering to a medical orientation ( $p < 0.0005$ ). There were no other significant differences between professionals beliefs on the validate factor of the PBAP-A across theoretical orientation.

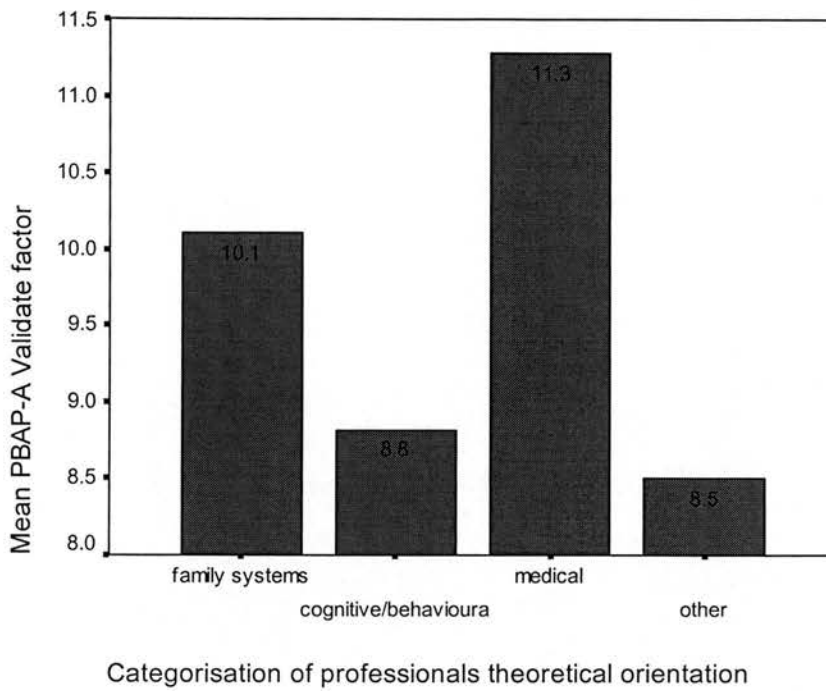


Figure 5, mean professionals beliefs about parents scores on the validate factor of the PBAP-A.

### *Summary*

This result indicates that professionals beliefs about parents did not vary based upon their professional grouping, age or number of years in practice. Post hoc hypotheses a, c and d could not therefore be accepted. Hypothesis b could be rejected across blame, inform and instruct factors but professionals beliefs about parents did differ on the validate factor based upon professionals preferred theoretical orientation. However, post hoc analysis did not reveal professionals using a cognitive behavioural approach to be more collaborative than all the other orientations as hypothesised, as this approach was not significantly more collaborative than professionals preferring family system or 'other' orientations. Professionals preferring a medical orientation were not less collaborative than those preferring a

family systems model. Hypothesis b could therefore also not be accepted on the validate factor.



# Discussion

## **Discussion**

The present study investigated aspects of the current state of partnership practice of professionals including the extent to which the philosophy of collaboration is reflected in professionals' beliefs and the degree to which these beliefs influence parents' perceptions of the helpfulness of professionals working with them and their child with learning disabilities. It was hoped that findings would help to inform professional practice.

### **Parents' perceptions of helpfulness**

Parents made a clear distinction in their perceptions of the helpfulness of professionals they named as the most helpful and those they named as the least helpful. Most helpful professionals were rated by parents to be significantly more helpful than least helpful professionals. This result was expected and matches previous research findings (Cournoyer and Johnson, 1991, Johnson et al, 1995). This suggests there is variation in the perceived helpfulness of professionals and that there may be a range in the extent to which professionals engage in collaborative behaviour. However, before drawing final conclusions this study sought to examine whether parents' perceptions of helpfulness truly reflected the practice of professionals being rated, or whether other factors may account for parents' ratings.

### **The influence of professionals' beliefs on parents' perceptions of helpfulness**

The professionals' beliefs about parents scale revealed that a greater percentage of professionals agreed with collaborative and disagreed with non collaborative

statements about parents. Some professionals indicated stronger agreement with collaborative beliefs about parents than others and a small number of professionals indicated disagreement with collaborative beliefs. Results appeared to differ from Johnson et al's (2000) findings which suggested a greater number of professionals hold beliefs that could impede collaborative practice. This may reflect the fact that the measure is being used in a different culture, or that as this study is three years later professionals beliefs may have become more collaborative, possibly due to the impact of social policy. It may also be due to the fact that the questionnaire is being used with professionals working with families of children with learning disabilities as opposed to families of children with mental health problems. Professionals may be more understanding towards families when their child has a learning disability rather than a mental health problem.

As previous researchers (Dunst et al, 1994d, Dunst et al, 1993, Johnson et al, 2000) have suggested that professionals' beliefs influence their practice the study focused upon whether the variation in parents' perceptions of professionals helpfulness could be accounted for by differences in professionals beliefs about parents of children with learning disabilities. No significant differences were found between the beliefs about parents of professionals named as either the most or least helpful. This suggested that the naming of most and least helpful professionals by parents is not determined by professionals' beliefs about parents and meant that hypothesis 1 could not be accepted. However, if professionals' beliefs are signals of their practice, this finding might suggest that parents' perceptions of professionals do not reflect the practice of the professionals whom they have rated. This would contrast with Dunst

et al's (1993) findings and would not support Johnson et al's (1994) hypothesis that professionals' beliefs influence parents' perceptions of them. It would also bring into question the conclusions of studies about professionals' behaviour based upon parents' perceptions (Byrne et al (1988), Sloper and Turner (1992), Johnson et al (1995), King et al (1996), Case (2001), Dunst et al (1994c) and Judge (1997)).

Dunst et al (1993) found that parents' ratings of professionals and professionals' beliefs are consistent with professional practice. Methodological differences in the design of the present study may account for the apparent contradiction between the present study's findings and Dunst et al (1993). In addition to differences such as the sample size and methods of data gathering and analysis, Dunst et al (1993) did not include an analysis of family or professional characteristics that may have contributed to differences in the parent-professional relationships observed and beliefs measured. The present study in contrast did measure such variables. As previous research has suggested there may be factors that limit the potential for partnership (Dale, 1996) including parental stressors (McConachie, 1991, 1994) and professional characteristics (Byrne et al, 1988, Dale, 1996) the potential impact of these factors on parents' perceptions of professional helpfulness was explored through post hoc analysis.

Post hoc analysis to hypothesis 1 found significantly more parents indicated understanding the role of the professional named as most helpful and not the role of the least helpful professional compared to parents who indicated understanding the role of the professional named as the least helpful professional but not the role of the

most helpful professional. This might suggest that in practice professionals named as most helpful are better at indicating what their role is with the family.

One implication of this finding is that some professionals need to improve their communication of their role to parents. This may be through spending time in the initial sessions with parents not only explaining ways in which they may be able to help parents, but also ways areas in which they may not be able to help. This opportunity may not always present itself for all professionals due to the differences in their roles. This was possibly the case in parents' choice of least helpful professional where approximately one third chose educational psychologists. These professionals would primarily be providing a service to schools rather than to parents. Their involvement with parents may be brief and mainly indirect through the school. Whilst this does not necessarily reflect a lack of collaborative practice on the part of the professional it may suggest that the professional should ensure that time is found to explain to parents fully how they fit in to services being provided for their child.

Clinical psychologists and paediatricians were most frequently rated as most helpful professionals by parents. Clinical psychologists may feature highly as a large proportion of the sample was gathered from their caseload, perhaps biasing parents' choice because parents had a higher level of contacts with them in comparison to other professionals. Choice of clinical psychologists might also reflect the focus on collaborative practice in clinical psychologists' training. The nature of clinical psychologists' role means they often provide emotional support, information, have

regular contact and provide ideas to help the child. This process may mean there are enhanced opportunities to develop an understanding relationship with parents that limitations on other professionals' roles do not allow. For example, the nature of the role of a social worker who might be involved in organising benefits for a family may present more opportunities for discord with families and less opportunity to take on board more explicitly the quality of the relationship with parents. Paediatricians were chosen as the most helpful professional the most often which may reflect the role paediatricians have in providing early information to parents about their child and the role paediatricians often have as a link person and coordinator of professional input. The fact that paediatricians and clinical psychologists were frequently cited as the most helpful may suggest that they would be a useful resource for consultation and training of other team members regarding collaborative working with parents.

Parents were more likely to indicate having ongoing contact with professionals they named as most helpful compared to professionals named as least helpful. Parents reported significantly more contact with most helpful professionals than those named as least helpful. This may indicate that parents had engaged better with them and so had more contact. This may be in part due to the fact that they have a clearer understanding of why the professional is involved in the care of their child. On the other hand, parents may be more likely to name the professional as the most helpful due to the increased amount of contact suggesting that professionals need to see parents as often as possible to be perceived as helpful.

Correlation analysis found that a number of variables did appear to influence parents' perceptions of professional helpfulness measured by the Helping Behaviour Checklist (HBCL-A). Caution is needed in interpreting these significant findings due to the moderately low correlations among variables. The relationship found between HBCL-A scores for most helpful professionals and support factors on the Family Support Scale (FSS) suggested that the more helpful professionals are perceived to be the more support families report receiving. Literature findings (e.g. McConachie, 1994) do suggest the benefits for parents of receiving informal support, and that professionals should attempt to mobilise informal support networks for families and provide groups, social outlets or respite. This finding may suggest that this is what is happening and because professionals have encouraged uses of these forms of support parents find them more helpful. It may also mean however, that when informal and social organisation sources of support are available parents rely less heavily on professionals and therefore have lower expectations when rating their helpfulness.

The relationship between HBCL-A scores for most helpful professionals and parental stress scales on the Parenting Stress Index (PSI) suggested that the more helpful these professionals are perceived to be the less stressed parents are. Whilst it has been suggested that professionals can act as moderators in parental stress (e.g. Sloper and Turner, 1992), which might explain this finding, no direction of causality can be ascertained from the data available. The finding may equally indicate that the level of parental stress influences the extent to which parents perceive professionals to be helpful.

If professionals' level of helpfulness does determine parental stress it might be expected, given the developmental nature of parent-professional relationships (Walker and Singer, 1993), that the more helpful these professionals are the longer they have been seeing parents or the more contacts they may have had to work with parents thereby reducing their stress. However no correlations were found between helpfulness scores of most helpful professionals and the number of contacts or length of time parents had had with them.

The relationship between the age of the parent and HBCL-A scores indicated that older parents are more likely to perceive professionals to be helpful. It is possible that this reflects differences in expectations of parents: for example, older parents may be more used to a professional as expert approach whilst younger parents may question this more. These differences may account for variation according to age.

The relationship between HBCL-A scores for most helpful professionals and lethargy/withdrawal factor scores for children on the Aberrant Behaviour Checklist (ABC) suggested that the more helpful professionals are perceived to be the less problems parents report with this aspect of children's behaviour. Parents whose child scores lower than others on the lethargy/withdrawal scale may have fewer needs and be less stressed and therefore be more likely to perceive professionals as helpful. Sloper and Turner (1992) found that perceptions of helpfulness were related to parents' perceived needs; however no measure of parental need was taken in this study. The lethargy/withdrawal factor did positively correlate with stress factors on



the PSI, which may be a mediating factor in the influence of lethargy/ withdrawal on parents perception of helpfulness of the professional named as most helpful.

Alternatively, it is possible that those professionals that are perceived as more helpful are providing more useful instruction to parents on how to deal with their child. Parents have expressed that they require professionals to: demonstrate problem solving skills (Dunst et al, 1994b); give practical help (Sloper and Turner, 1992); and to explain how parents could help their child (Cournoyer and Johnson, 1991). If more helpful professionals are doing this it may account for parents reporting lower lethargy/withdrawal behaviour in their child.

The intercorrelations between the most helpful professionals HBCL-A scores and support, stress and child's behaviour factors might also suggest that these family characteristics have a joint mediating impact upon parents' perceptions of the most helpful professional. For example, if a family has a child with high problems on the lethargy/withdrawal factor and little informal support they may experience increased stress making them less able to benefit from professional input which leads to a lower rating of the most helpful professional. This type of possibility would concur with McConachie's (1994) stress/coping model in that it connects multiple factors that can influence parental stress. However, direction of causality between variables can not be established.

It was interesting that age, support, stress and child's problem behaviour factors only correlated with HBCL-A scores for most helpful professionals and not for least

helpful professionals. This might be due to the low number of matches possible between the HBCL-A and least helpful professionals' beliefs questionnaires which reflects the low number of responses of least helpful professionals. Interpretation of this lack of correlations must be treated with caution. However, it might suggest that even the professionals named as most helpful become less effective the more stressed parents are, the less informal and social organisation support they receive, the older they are and the more problems they experience with their child's lethargy and withdrawal. The least helpful professionals have no impact at all on these factors as they are perceived as unhelpful regardless of them.

One possible explanation for why even the most helpful professionals become less effective may be that parents' need for services do not match what professionals can provide. As Dale (1996) pointed out partnership may break down if the professional has less resource power than the parent wants. This would mean that however helpful professionals are in practice, they may not always be able to provide necessary resources for parents. This may be due to a lack of availability of resources including a lack of coordination of services. The level of resources available to parents was not measured in this study, however it was reported by Simpson and Hyland (2003) that parents in the Fife area do not have access to a clear multi-agency framework for service delivery.

The implication here may *not* therefore be that professionals need to be trained to improve their practice, but that improvement in coordination of service delivery and an increase in resources may be what is required to effectively help parents. One way

to tackle this problem that is advocated by Byrne et al (1988) and Sloper and Turner (1992) is the introduction of a named 'link' worker to coordinate services for a particular family.

Whilst a link worker may be able to improve service provision it may be up to the professional working with the parent to ensure that they clearly communicate their role and the extent of the resources they may be able to provide to the parent. As advocated by Dale (1996) the professional may need to negotiate their role if the parents' expectations of them do not match what they can provide. This may mean the professional negotiating to play a role in helping parents to obtain required resources. This position may not always suit particularly stressed parents, with problems with their child and a lack of support, and lead these parents to perceiving professionals as less helpful.

It is also possible that there is variation in the practice of professionals named as the most helpful, that account for the correlations between HBCL-A and stress, support and child's lethargy/withdrawal factors in most helpful professionals but not least helpful professionals. If this is so this might be reflected in professionals' beliefs about parents' scores whereby: the more helpful the professionals named as most helpful were perceived to be by parents on the HBCL-A the more collaborative professionals beliefs about parents would be on the PBAP-A. Post hoc ANCOVA examined the relationship between parents perceptions of most helpful professionals on the HBCL-A and professionals beliefs on the PBAP-A *whilst* adjusting for stress, age, support and child's lethargy/withdrawal factors and did not find any significant

effects. This perhaps further suggested that it is factors intrinsic to the parent that determine perceptions of helpfulness not differences in the professionals themselves.

The only variable to significantly correlate with parents' ratings of the least helpful professional was parents' beliefs (on the Parents Beliefs about Parents Scale) on the validate factor. This negative correlation indicated that the less parents endorsed collaborative beliefs about parents on the validate factor the more likely they were to rate the least helpful professional as more helpful. This might suggest that the less parents believe they need to be validated the less likely they are to rate the least helpful professional poorly. It may however suggest that parents that experience more helpful professionals are more likely to agree that parents should be validated.

The lack of replies from professionals named as the least helpful may suggest that these professionals were reluctant to indicate their beliefs about parents of children with learning disabilities. It may also be that most helpful professionals were more easily contactable as they tended to be professionals parents had ongoing contact with whilst least helpful professionals may have been seen a longer time ago and were possibly no longer with the service.

### **Congruence between parents and professionals' beliefs about parents.**

Hypothesis 2a examined whether parents' and professionals' beliefs about parents were congruent. Parents were found to hold beliefs more in line with a collaborative philosophy than professionals although the difference was only significant on blame, inform and instruct factors of the beliefs about parents scales. Hypothesis 2A was

therefore accepted across blame, inform and instruct factors but not on the validate factor. The Providers Beliefs about Parents Scale (Johnson et al, 1994) did not provide cut off points for what represents a sufficient level of beliefs required to work collaboratively with parents. In measuring the beliefs of parents about parents, this study provided a method of gauging professionals' beliefs by comparison with parents' beliefs. If parents beliefs about parents represent what professionals should aspire to then the results of this study suggest that professionals fall short in the extent to which they hold beliefs that are required for partnership work on the blame, inform and instruct factors. Professionals therefore may require additional training in understanding the parents' situation in order to reduce blame attributions and training in sharing information with parents more openly. However, as professionals appear to hold similar beliefs to parents on the validate factor, this may suggest that professionals hold beliefs at a 'good enough' level for collaborative work with parents, and that training would not be required to focus on this area.

Alternatively, findings that parents and professionals beliefs about parents significantly differ might be expected within the context of Dale's (1996) negotiating model which encompasses the diversity and discrepancies between parents and professionals. It may be that professionals in this study endorse collaborative statements less than parents based on their clinical experience. For example, if a professional is aware that a family are experiencing a particularly stressful time, she or he may withhold certain information until she or he feels that the family are ready to take the information on board. Provided this is helpful to the parents this may be a more sensible way for a professional to operate than overwhelming parents with too

much information at once. In addition, potential constraints on partnership due to differences in parents' and professionals' beliefs may be overcome if the professional is honest about her or his view and negotiates solutions to this with parents.

The issue of what exactly is 'good enough' is difficult to resolve. However, it has been established that as a whole professionals do generally endorse collaborative statements about parents and as identified in examination of hypothesis 2b, parents' beliefs do not differ significantly more from professionals they named as least helpful compared with professionals they named as most helpful on blame, inform and validate factors. This perhaps suggests that professionals' beliefs on these factors are 'good enough' for them not to influence parents' choice of the most and least helpful professionals. The instruct factor however was an exception as whilst hypothesis 2b could not be accepted across blame, inform and validate factors it was accepted on the instruct factor.

On the instruct factor the degree of congruence between parents and most helpful professionals was significantly more than between parents and the least helpful professionals. This might suggest that parents' decisions regarding who was the most and least helpful professional they worked with was influenced by the extent to which professionals held the same beliefs as them on the instruct factor. If professionals indicated beliefs in accordance with parents' beliefs on this factor they were significantly more likely to be named as the most helpful professional. Congruence on the instruct factor reflects the fact that parents and most helpful professionals' both endorsed statements that professionals should tell parents what to

do to help their child. As reported above previous research has suggested parents want professionals to explain how parents could help their child (Cournoyer and Johnson, 1991).

It must be noted that overall parents 'agree' but do not 'strongly agree' with this factor. It may be that the provision of direct instruction to parents is something that some parents want more than others and that the professional must negotiate whether or not they provide direct instruction. From this point of view it is possible that professionals agreement with the instruct factor on the PBAP-A does not strictly indicate a collaborative perspective. Professionals that do not agree with this statement may be doing so as they would only provide instruction if this was a negotiated role with a parent. On the other hand they may not agree with the instruct factor because they do not believe parents should be involved in the process of helping children with learning disabilities, or as Johnson et al (2000) suggested because they believe that parents are the ones who need treatment and therefore do not teach parents skills because this will not get to the 'root' of the problem. The factor is perhaps unclear and clarification of this issue may be possible if the instruct factor statements were modified. For example, item 11 may be changed from: 'It is therapeutically sound for professionals to tell parents directly what they should do to help their child' to: 'It is therapeutically sound for professionals to tell parents directly what they should do to help their child if requested to by parents'.

### **The influence of professionals' characteristics on their beliefs about parents**

As a post hoc hypothesis this study examined whether professionals beliefs about parents varied at all depending upon the characteristics of the professional. Professionals' beliefs did not differ according to which professional grouping they belong to, their age or their number of years in practice meaning these hypotheses could not be accepted. The lack of difference across discipline was in contrast to findings by Johnson et al (1997), who found variation in beliefs across disciplines. However it does perhaps support Sloper and Turner's (1992) suggestion that the personality of the professional and the relationship formed with the family is more important than their discipline.

Professionals' beliefs about parents on the validate factor varied across their reported theoretical orientation. This may reflect professionals training as those indicating use of medical theory indicated less collaborative views than professionals using a cognitive/behavioural approach, which promotes collaborative practice. It is possible that professionals working to a medical model view themselves as more expert than the parent and are therefore less likely to endorse statements on the validate factor, whilst those using a cognitive/behavioural approach may be more keen to involve and validate parents. The post hoc hypothesis could not however be accepted on the validate factor of the PBAP-A either as the beliefs of professionals adhering to medical and cognitive behavioural orientations did not significantly differ from all other preferred orientations on this factor. In addition, despite some differences in beliefs across orientations, all professionals' beliefs indicated agreement with collaborative statements which ever orientation they preferred.



## **Limitations**

The size of the sample obtained for the study had weak power. More meaningful conclusions from the data may be drawn with a larger sample. However, if this study is viewed as a pilot for future research with a larger sample a number of further limitations must be considered.

The nonrandom selection of the sample limited the external validity of the studies representation of parents of children with learning disabilities in general. Participants were either in touch with or on the waiting list for clinical psychology, community nurse services, a consultant paediatrician or were members of parent support groups. Those in touch with services may be so due to particular problems for which they are seeking help. These parents may therefore have been assessed at a particularly vulnerable time. Parents in touch with parent support groups may be proactive in campaigning for resources and may be more empowerment focused.

Attempts to include a wider representation of parents of children with learning disabilities included seeking permission to approach parents of children with learning disabilities through schools. It was hoped this would have increased the variability in the sample though including parents that were not in contact with services at the present time and parents that had adapted well to their child with a learning disability. It was therefore disappointing that the local education authority in Fife declined to give permission for the researcher to approach parents through the local schools.

Professionals were also not fully represented. Less than half professionals invited to participate returned questionnaires. There may have been self selection bias in the professionals that did return questionnaires. However, reasons for professionals not returning questionnaires were not obtained.

### *Measures*

The lack of appropriate measures available that can be administered to both parents of children with learning disabilities and professionals working with them meant that this study relied upon the adaptation of the PBAP (Johnson et al, 1994) and the HBCL (Cournoyer and Johnson, 1991). This was not ideal as it compromised the reliability and validity of the measures and resulted in the study relying on non standardised measures. Future research is needed to develop standardised measures to allow an examination of the parent professional relationship.

Relying on professionals' beliefs about parents to gain an insight into their practice was limiting. Whilst they may hold collaborative beliefs these may not be applied in practice. A more objective method of measuring professionals' behaviour may have been more valid and reliable. One way may have been to have a neutral observer rating professionals working with parents. This method in itself may alter the professionals' interaction with a parent. Relying on parents and professionals perspectives may therefore be the most practical option available. A questionnaire that asks more direct questions about partnership may be needed including questions

that establish whether professionals feel able to put a collaborative philosophy into practice and if not what limits this.

Asking professionals their beliefs about *each* family they work with might allow for an increased insight into collaboration. The PBAP-A asks professionals about parents in general. It may be that professionals' beliefs about parents vary dependent upon the family with which they are interacting. For example, professionals' intervention may be influenced by whether they attribute the patients' life events to controllable or uncontrollable causes, as was found by Brewin (1984). Professionals may blame some parents for their problems whilst being more sympathetic towards others. The consistency of professionals' beliefs about parents across families may therefore be an important aspect of the collaborative process that this study was unable to assess. Using a measure of professionals' beliefs about individual families would also have allowed for an increase in the number of matches between parents and professionals. The same professionals being named by different parents in this study limited the number of matches that could be analysed. However, it might be considered a strength that this study asked professionals their views about families in general, as only asking about individual parents may restrict insight into their overall beliefs about requirements for engaging in collaborative relationships with parents.

Parents were not restricted temporally when completing questionnaires about professionals. They may, for example, have completed the HBCL-A whilst considering a professional whom they had not had contact with for many years. The parent may have been extremely stressed at the time that they were in contact with

the professional but no longer be as stressed at the time when completing the questionnaire. This would therefore not be reflected in the parents' present PSI score. The professional that was unhelpful may have since been influenced by changes in social policy and have become more collaborative in his or her practice. Thus, the present beliefs of the professional may not reflect the beliefs that had led to unhelpful practice. Whilst there was ongoing contact between over half of the professionals named and parents, there are limitations to the reliability of examining parent-professional relationships that were not ongoing. Future studies may wish to limit parents to only rating professionals with whom they have ongoing contact.

Dale (1996) outlined circumstances which limit partnership and as McConachie's (1994) stress and coping model identified there are multiple factors that may impact upon parents' well being. Findings in the present study indicated that a number of such factors influenced parents' perceptions of professionals' helpfulness. This would suggest future studies should also take a multivariate approach and investigate variables that this study was not able to measure. This includes measuring resources available to parents and their level of unmet needs which may impact upon parents' rating of professionals as might their cognitive coping style and the influence of additional life stressors.

Whilst measuring parents' perceptions of most and least helpful professionals allowed for an insight into parents views about a range of individual professionals, these views may need to be placed within the context of the whole service that parents receive. For example, perceptions of the helpfulness of professionals named

as most helpful may be worse if the parent is not satisfied that overall service provision is meeting their and their child's needs. Additional contextual factors that might influence parents' perceptions of helpfulness may be whether there are any limiting parameters to the parent-professional relationship, and whether services are provided to parents at home or within a healthcare setting. Future studies should include measures of these factors.

The study was limited in the extent to which it measured influences on professionals' beliefs. Future studies may wish to include measures of organisational structure including social policies adhered to and the scope of resources available to professionals. Measurement may also cover the extent to which their work in partnership with other professionals affects their practice, and the influence of their mental health on their practice.

## **CONCLUSION**

This study found that whilst parents do meaningfully differentiate between the helpfulness of professionals they name as most or least helpful this does not reflect a difference in the extent to which professionals' appear to endorse collaborative practice, as measured by professionals' beliefs about parents. A number of factors intrinsic to the parent did differentiate between their choice of most and least helpful professionals. Parents were more likely to name professionals as most helpful rather than least helpful if they understood their role, had ongoing contact and a larger number of contact with them, and had a greater degree of congruence with professionals' beliefs about parents on the instruct factor. It would appear that

parents' age, stress, support and child's lethargy factors influence the way in which they rate most helpful professionals but not least helpful professionals, whilst parents beliefs about parents on the validate factor contributes to the variance in ratings of least helpful professionals. Professionals endorse collaborative statements significantly less than parents on the blame, inform and instruct factors and professionals views on the validate factor vary according to their theoretical orientation.

Whilst there are various limitations this study has been able to identify key areas in which professionals might improve their practice. The findings may be of value to training organisations for professionals including the new NHS Education for Scotland, which has stated it aims to prioritise the provision of training in communication and involvement skills. This study's findings would suggest the focus on communication may be to ensure professionals are clear about their role and the service they provide and that training of involvement skills may be particularly relevant for professionals utilising a medical theoretical orientation. Findings also highlight the fact that parents beliefs about professionals are not purely determined by professionals practice and that in addition to focusing on professional skills to improve partnership, attention may also need to be paid to providing sufficient resources, and improved coordination of services perhaps by introduction of a link person, to ensure professionals can form as effective relationship with parents as possible.

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# **Appendices**

## **Appendix One**

Mr C Burke  
Department of Clinical Psychology  
Queen Margaret Hospital  
Whitefield Road  
DUNFERMLINE  
Fife KY12 0SU

**EDUCATION SERVICE**

**Direct Line - David MacKenzie**  
**01592 413658**

Email – david.mackenzie@fife.gov.uk

Our ref: DM/KF

14 March 2003

Dear Mr Burke

**RESEARCH PROPOSAL**

I have discussed your recent research proposal with colleagues in the Psychological Service. Thank you for meeting with them recently and taking account of their concerns in your questionnaire to parents. I understand that you are seeking to access a sample of parents through Fife Special Schools. While I appreciate the potential administrative convenience of this for you I am concerned that despite your letter to parents there could be confusion about the origins and purpose of the research if initial contact was from schools as proposed. At worst this confusion could impact on relationships between parents and schools; it could also generate workload issues as parents could still understandably contact schools for advice or clarification in relation to it. In view of this it is my decision not to distribute your contact letter through schools.

I regret we are unable to help you on this occasion and hope you are able to access a sample group by some other means.

Yours sincerely



David MacKenzie  
Senior Manager (Support for Learning)

## Appendix Two



Dear (parent)

**Study of parents' views about special needs services and their helpfulness.**

Please find enclosed information about a study involving parents of children with special needs. You are being invited to take part in this study because your child is attending a special needs school in Fife.

**Your opinions and experiences will be of value to us in developing future services.** However, please note that you are under no obligation to participate in this research. A decision not to participate will not in any way alter the services or treatments that you or your child would normally receive.

Please find a tear off slip below for you to return indicating whether or not you wish to take part in this study. A stamped addressed envelope is enclosed for you to return the slip.

- If you indicate that you would like to take part in the study I will contact you to arrange a suitable time to meet.
- Should I not hear from you within two weeks I will phone to see if you wish to take part.

Many thanks for your consideration of this project. If you have any questions please do not hesitate to contact myself, Chris Burke, at: Psychology Department, Lynebank Hospital, Dunfermline, Fife. Telephone: 01383 623 623, extension 5393.

Yours sincerely,

Christopher Burke  
Main investigator,  
Clinical Psychologist in Training.

Marie Renaud  
Research Supervisor,  
Clinical Psychologist.

# Appendix Three



## Parent Participant information sheet

### Study of parents' views about special needs services and their helpfulness.

You are being invited to take part in this study that is investigating the views of parents' of children with special needs about services received. In particular you will be asked about the professional workers you have met (e.g. Paediatricians, Health Visitors, Community Nurses etc). The study also looks at whether using special needs services is helpful to parents. The study aims to extend previous research that has shown the importance of the parent-professional relationship in engagement to services.

#### Why have I been chosen?

- You have been chosen for this study because you are the parent of a child with special needs. Your experiences, be they positive or negative, are valuable in raising awareness of issues for parents. It is hoped that information you provide can help improve services in the future both for you and for other parents.
- Over 150 parents who live in Fife are being invited to take part in this study. Parents are being contacted if their child has ever been referred to a special needs service or if their child attends a special needs school.
- The research is being carried out over a six-month period between February and August 2002.

#### What will happen if I take part?

- If you agree to participate, Chris Burke, the main study investigator, will arrange to meet you *just once* to go through some questionnaires.
- The questionnaires will ask about:
  - Your beliefs about being a parent of a child with special needs.
  - Your experiences regarding healthcare professionals you have met.
  - How you cope with your child and about your child's behaviour.
- This questionnaire interview will last approximately one hour.
- All information collected will remain *entirely confidential*. The only person with access to any information will be the main investigator (Chris Burke). Your name will not be included in any published results and you will not be identified by any of the answers that you give on the questionnaires that you complete.

#### Do I have to take part?

- Your participation is *entirely voluntary*.
- If you *do* decide to take part you will be asked to sign a consent form. You will be given a copy of this information sheet and the signed consent form to keep.
- If you choose *not* to participate or withdraw from the study, you and your child's access to services and treatments will *not* be affected in any way.

If you have any questions please do not hesitate to contact myself, Chris Burke, at: Psychology Department, Lynebank Hospital, Dunfermline, Fife. Telephone: 01383 623 623, extension 5393.

## Appendix Four



### Reply Slip

I would / would not be happy to participate in the research project entitled:

**Parent – professional collaboration: implications for service delivery to parents of children with special needs.**

Signed:

Name:

Your child's name:

Address:

Telephone number:

Date:

## Appendix Five



Psychology dept  
Lynebank Hospital  
Fife  
KY11 4UW

01383 623623 ext.5393

Dear

Thank you for agreeing to take part in the study of parents' views about special needs services. Please find enclosed a copy of the questionnaire, which usually takes between 45 minutes to 1 hour to complete.

Please could you sign the consent form at the start of the questionnaire pack. Information that you provide within the questionnaire will be kept entirely confidential.

A stamped addressed envelope has been enclosed for you to return the questionnaire.

Many thanks for your time. If you have any questions please do not hesitate to contact myself, Chris Burke, at: Psychology Department, Lynebank Hospital, Dunfermline, Fife. Telephone: 01383 623 623, extension 5393.

Yours sincerely,

Christopher Burke  
Main investigator,  
Clinical Psychologist in Training.

Marie Renaud  
Research Supervisor,  
Clinical Psychologist.

## Appendix Six



### Parent Consent Form

**Please sign the consent form to indicate that you have agreed to take part.**

Investigators: Chris Burke, Clinical Psychologist in training, Marie Renaud, Clinical Psychologist.

- I agree to take part in this study.
- I have read this Consent Form and Participant Information Sheets and had the opportunity to ask questions about them. (Please call Chris Burke on 01383 623 623 ext: 6051, if you would like to ask further questions).
- I understand that I am under no obligation to take part in this study and that a decision not to participate will not in any way alter the services or treatments that I or my child would normally receive.
- I understand that I have the right to withdraw from this study at any stage and that to do so will not in any way alter the services or treatments that I would normally receive.

Signature of Participant .....

Name of Participant .....

Signature of Investigator.....

Date:.....

3 copies to be made:

1. copy to participant
2. copy to the investigator
3. copy to be filed in relevant case notes



## Appendix Seven



Dear (Professional)

**Parent – professional collaboration: implications for service delivery to parents of children with special needs.**

I would like to invite you to take part in a research study investigating parent-professional collaboration within services for children with learning disabilities. Please find enclosed:

- a questionnaire investigating your beliefs about parents of children with learning disabilities.
- an information sheet on this research
- a consent form.
- a stamped addressed reply envelope.

I would be very grateful if you would complete the questionnaire and return it to me in the enclosed stamped addressed envelope. The questionnaire should take approximately 20 minutes to complete, (based on a pilot trial). Please could you sign and return the consent form along with the questionnaire if you take part in this study.

Many thanks for your time in completing the questionnaire. I hope to circulate a report on my findings later this year.

Yours sincerely,

Christopher Burke  
Main investigator,  
Clinical Psychologist in Training.

Marie Renaud  
Research Supervisor,  
Clinical Psychologist.

## Appendix Eight



### Professional participant information sheet

#### **Parent – professional collaboration: implications for service delivery to parents of children with special needs.**

You are being invited to take part in this study that is investigating the relationship between parents of children with special needs and healthcare professionals. The study also looks at whether using healthcare services is helpful to parents of children with special needs. The study aims to extend previous research that has shown the importance of the parent-professional relationship in engagement to services.

#### **Why have I been chosen?**

- You have been chosen for this study because you are a professional working with parents of children with special needs. It is hoped that your perceptions can provide an insight into the level of agreement between professionals and parents beliefs about parents of children with special needs.
- Over 100 professionals who work in Fife are being invited to take part in this study.
- The research is being carried out over a six-month period between February and August 2002.

#### **What will happen if I take part?**

- If you agree to participate, you will be asked to complete **one** questionnaire asking you about your beliefs about parents of children with special needs.
- This questionnaire will take approximately 20 minutes to complete, (based on a pilot trial).
- All information collected will remain *entirely confidential*.
- The only person with access to any information will be the main investigator (Chris Burke). Your name will not be included in any published results and you will not be identified by any of the answers that you give on the questionnaires that you complete.

#### **Do I have to take part?**

- Your participation is *entirely voluntary*.
- If you *do* decide to take part you will be asked to sign a consent form. You will be given a copy of this information sheet and the signed consent form to keep.

If you have any questions please do not hesitate to contact myself, Chris Burke, at Special needs Psychology Department, Lynebank Hospital, Dunfermline, Fife. Telephone: 01383 623 623, extension 5393.

## Appendix Nine



### Professional Consent Form

**Parent – professional collaboration: implications for service delivery to parents of children with learning disabilities.**

- I am happy to take part in this study.
- I have read this Consent Form and the Participant Information Sheets and had the opportunity to ask questions about them\*.
- I understand that I am under no obligation to take part in this study.
- I understand that I have the right to withdraw from this study at any stage.

Signature of Participant .....

Name of Participant .....

Signature of Investigator.....

Date:.....

Please sign both copies of the consent form enclosed, retaining one for your personal records and sending one back to the investigator along with your questionnaire.

\*If you have any questions please do not hesitate to contact myself, Chris Burke, at Learning Disabilities Psychology Department, Lynebank Hospital, Dunfermline, Fife. Telephone: 01383 623 623, extension 5393.

## Appendix 10



Dear (parent)

**‘Parent – professional collaboration: implications for service delivery to parents of children with special needs’**

Thank you for your participation in this study. During the examination process of my research it was felt that the information sheet sent to you did not fully explain the use of your questionnaires for the study, in particular, the questionnaires you completed naming the most and least helpful professionals you had contact with in relation to your child and indicating the helpfulness of named professionals.

The information sheet sent to you did not make it clear that the study examined the relationship between responses given by you and by professionals you named. Furthermore, your questionnaires were identified by name in order to be directly linked to and compared with the questionnaires completed by the professionals you named. Please note professionals were not asked to answer questions about their experience of working with you.

Under no circumstances have questionnaires you completed been directly disclosed to any professionals including those you identified as most or least helpful. All information collected remains entirely confidential and is used for purposes of research only.

Should you have any questions regarding the study please do not hesitate to contact me on 01383 623623 ext: 6051. You are at liberty to withdraw your consent for your questionnaire being used within this study. Should you wish to withdraw please complete the reply slip attached and return it within the stamped addressed envelope provided and your data will be destroyed.

Thank you for your attention to this letter.

Yours sincerely,

Christopher Burke  
Main investigator,  
Clinical Psychologist in Training.

Marie Renaud  
Research Supervisor,  
Clinical Psychologist.

### **Withdrawal of consent form**

Please withdraw my questionnaires from use within the study 'Parent – professional collaboration: implications for service delivery to parents of children with special needs'.

**Name:** .....

**Address:** .....

**Your Child's Name:** .....

If you do wish to withdraw please return this slip to Chris Burke at Psychology Department, Queen Margaret Hospital, Dunfermline, Fife using the stamped addressed envelope enclosed. Please note that withdrawal from the study will not affect you and your child's access to services in any way.

## Appendix 11



Dear (professional)

**‘Parent – professional collaboration: implications for service delivery to parents of children with special needs’**

Thank you for your participation in this study. During the examination process of my research it was felt that the information sheet sent to you did not fully explain the use of your questionnaire for the study. You completed a questionnaire indicating your beliefs about parents of children with a learning disability.

The information sheet sent to you did not make it clear that the study examined the relationship between responses given by you and by parents who may have named you as the most or least helpful professional with whom they have had contact. Furthermore, your questionnaire was identified by name in order to be directly linked to and compared with questionnaires completed by parents who might have named you.

Under no circumstances has the questionnaire you completed been directly disclosed to any parents. All information collected remains entirely confidential and is used for purposes of research only.

Should you have any questions regarding this study please do not hesitate to contact me on 01383 623623 ext: 6051. You are at liberty to withdraw your consent for your questionnaire being used within this study. Should you wish to withdraw please complete the reply slip enclosed and return it within the stamped addressed envelope provided and your data will be destroyed.

Thank you for your attention to this letter.

Yours sincerely,

Christopher Burke  
Main investigator,  
Clinical Psychologist in Training.

Marie Renaud  
Research Supervisor,  
Clinical Psychologist.

### **Withdrawal of consent form**

Please withdraw my questionnaire from use within the study 'Parent – professional collaboration: implications for service delivery to parents of children with special needs'.

**Name:**.....

**Profession:**.....

**Address:**.....

If you do wish to withdraw please return this slip to Chris Burke at Psychology Department, Queen Margaret Hospital, Dunfermline, Fife using the stamped addressed envelope enclosed.

## **Appendix 12**



**Mr. Chris Burke**  
**Clinical Psychology Department**  
**Queen Margaret Hospital**  
**DUNFERMLINE**

Date 23<sup>rd</sup> December 2003  
Your Ref  
Our Ref KM/CM

Enquiries to Cathy Mitchell  
Extension 336 or 217

Dear Chris

Thank you for your enquiry regarding your letter to participants in your dissertation study. I have conferred with the Secretary of the Fife LREC and I would respond as follows:

1. The Ethics Committee were satisfied with the proposal you submitted in its entirety.
2. You are writing to participants to clarify points re anonymised data already collected and comparison of this data from families with that collected from professionals.

This process is regarded as part of an ongoing approved study and does not change the sub mission previously made, so does not require any further input from the Ethics Committee.

I hope this clarifies the situation for you.



Awarded for excellence  
to Nutrition and Dietetic Department



Awarded for excellence  
to Fife Community Dental Service

Chairman: Dr James Gallacher  
Chief Executive: George J Brechin

## Appendix 13



Dear Parent of

**Study of parents' views about special needs services and their helpfulness.**

Please find enclosed information about a study involving parents of children with special needs. You are being invited to take part in this study because you are the parent (or principal carer) of .

Your opinions and experiences will be of value to us in developing future health, education and social services. However, please note that you are under no obligation to participate in this research. A decision not to participate will not in any way alter the services or treatments that you or your child would normally receive.

Please find a slip enclosed for you to return indicating whether or not you wish to take part in this study. A stamped addressed envelope is enclosed for you to return the slip. If you indicate that you would like to take part in the study a questionnaire pack will be sent to you.

Many thanks for your consideration of this project. If you have any questions please do not hesitate to contact myself, Chris Burke, at: Psychology Department, Queen Margaret Hospital, Dunfermline, Fife. Telephone: 01383 623 623, extension 6051.

Yours sincerely,

Christopher Burke  
Main investigator,  
Clinical Psychologist in Training.

Marie Renaud  
Research Supervisor,  
Clinical Psychologist.

# Appendix 14



## Parent Participant information sheet

### **Parent – professional collaboration: implications for service delivery to parents of children with special needs.**

You are being invited to take part in a study that is investigating the views of parents' of children with special needs about professionals (e.g. Paediatricians, Health Visitors, Community Nurses etc) they have met in relation to their child. The study looks at whether parents perceive the professionals they have had contact with to be helpful and whether these views are influenced by the beliefs of professionals about parents of children with special needs. It also looks at how stress, support and children's behaviour might influence parents' perceptions.

#### **Why have I been chosen?**

- You have been chosen for this study because you are the parent of a child with special needs.
- Over 150 parents who live in Fife have been invited to take part in this study. Parents are being contacted if their child has ever been referred to a special needs service or if their child attends a special needs school.

#### **What will happen if I take part?**

If you agree to participate you will be asked to complete a series of questionnaires covering:

- Your perceptions of the most and least helpful professionals you have met in relation to your child.
- Your beliefs about being a parent of a child with special needs.
- Your stress levels, your support network and your child's behaviour.

It should take approximately forty five minutes to complete the questionnaires.

Professionals who work with families of children with special needs are also being asked to complete a questionnaire about their general attitudes towards parents of children with special needs. **Your questionnaires will be identified by name and directly linked to the questionnaires completed by the professionals you named.** Under no circumstances will questionnaires be directly disclosed to anyone. All information collected is entirely confidential.

#### **Do I have to take part?**

Your participation is *entirely voluntary*. If you *do* decide to take part you will be asked to sign a consent form. You will be given a copy of this information sheet and the signed consent form to keep. If you choose *not* to participate or withdraw from the study, you and your child's access to services and treatments will *not* be affected in any way.

If you have any questions please do not hesitate to contact myself, Chris Burke, at: Psychology Department, Queen Margaret Hospital, Dunfermline, Fife. Telephone: 01383 623 623, ext: 6051.

## Appendix 15



### Professional participant information sheet

#### **Parent – professional collaboration: implications for service delivery to parents of children with special needs.**

You are being invited to take part in a study that is investigating the views of parents' of children with special needs about professionals they have met in relation to their child. The study looks at whether parents perceive the professionals they have had contact with to be helpful and whether these views are influenced by the beliefs of professionals about parents of children with special needs. It also looks at how stress, support and children's behaviour might influence parents' perceptions.

#### **Why have I been chosen?**

- You have been chosen for this study because you are a professional working with parents of children with special needs.
- Over 100 professionals who work in Fife are being invited to take part in this study.

#### **What will happen if I take part?**

If you agree to participate, you will be asked to complete **one** questionnaire asking you about your beliefs about parents of children with special needs. This will take approximately 10 minutes to complete.

Parents will be asked about:

- their perceptions of the most and least helpful professionals they have met in relation to their child.
- their beliefs about being a parent of a child with special needs.
- their stress levels, support network and child's behaviour.

**Your questionnaire will be identified by name and directly linked to questionnaires completed by parents who may have named you as the most or least helpful professional they have had contact with.** Under no circumstances will questionnaires you completed be directly disclosed to anyone. All information collected is entirely confidential.

#### **Do I have to take part?**

Your participation is *entirely voluntary*. If you *do* decide to take part you will be asked to sign a consent form. You will be given a copy of this information sheet and the signed consent form to keep.

If you have any questions please do not hesitate to contact myself, Chris Burke, at: Psychology Department, Queen Margaret Hospital, Dunfermline, Fife. Telephone: 01383 623 623, ext: 6051.

## **Appendix 16**

Mr Christopher Burke  
Clinical Psychologist in Training  
Queen Margaret Hospital  
Whitefield Road  
Dunfermline  
Fife

Date	10 February 2003
Your Ref	HL/GA
Our Ref	AJS/SAM/L602 040203 954
Enquiries to	Mrs Alison Smit
Extension	1003
Direct Line	01334 421003
Email	<a href="mailto:alison.smit@fifenhhsboard.scot.nhs.uk">alison.smit@fifenhhsboard.scot.nhs.uk</a>

**PLEASE QUOTE LREC REFERENCE ON ALL CORRESPONDENCE**

Dear Mr Burke,

**FIFE LREC REFERENCE NUMBER: 954**

**PARENT - PROFESSIONAL COLLABORATION: IMPLICATIONS FOR SERVICE DELIVERY TO PARENTS OF CHILDREN WITH SPECIAL NEEDS**

I refer to your letter dated 28 January 2003 giving details of changes that have been made to information sent out to applicants in relation to the above study. I write to confirm that this was **approved** at the Fife Local Research Ethics Committee meeting held on 4 February 2003.

Yours sincerely

**ALISON SMIT (MRS)**

Secretary  
Fife Local Research Ethics Committee



Chair Esther Robertson  
~~Interim~~ Chief Executive George Brechin  
*Fife NHS Board is the common name of Fife Health Board*

# Appendix 17

## Parent and child information (Questionnaire 1)

Please complete the following information by answering the questions and ticking the appropriate box where necessary.

### Questions about your child with special needs:

- 1 How old is your child?
 

2-5 ☐  
 6-9 ☐  
 10-14 ☐  
 14-19 ☐  
 Male ☐  
 Female ☐  
 Yes ☐  
 No ☐
- 2 Gender of your child:
- 3 Does your child have a diagnosis?

If yes please state diagnosis/severity:

- 4 .....  
What do you believe caused your child to have special needs?

- 5 What day services does your child use?
 

Day Care ☐  
 Assessment centre ☐  
 School (name): ☐  
 .....  
 Other: ☐  
 .....

### Questions about you:

- 6 Please state your relationship to the child?
 

Mother ☐  
 Father ☐  
 Male principal carer ☐  
 Female principal carer ☐  
 18-24 ☐  
 25-35 ☐  
 36-45 ☐  
 46-55 ☐  
 55-65 ☐  
 65+ ☐  
 Unemployed ☐  
 Employed ☐  
 Full Time Carer ☐  
 single ☐  
 married ☐  
 cohabiting with partner ☐  
 separated ☐  
 divorced ☐  
 widow/widower ☐  
 Unemployed ☐  
 Employed ☐  
 Full Time Carer ☐
- 7 Age
- 8 Employment status:
- 9 Marital status
- 10 Partners employment status:

Questions about your use of professional services:

- 11 Do you think involvement of services is important for helping your child?

Yes ☐  
No ☐  
Don't know ☐

**12. Please tick the box (and name) which of the following professionals you are presently seeing or have seen at any time since your child was born:**

Please note: Information you provide is entirely confidential

Clinical Psychologist ☐

Name(s):

Presently seeing:.....

Previously seen:.....

.....

Social worker ☐

Name(s):

Presently seeing:.....

Previously seen:.....

.....

Educational Psychologist ☐

Name(s):

Presently seeing:.....

Previously seen:.....

.....

Occupational Therapist ☐

Name(s):

Presently seeing:.....

Previously seen:.....

.....

Paediatrician ☐

Name(s):

Presently seeing:.....

Previously seen:.....

.....

Health Visitor ☐

Name(s):

Presently seeing:.....

Previously seen:.....

.....

Psychiatrist ☐

Name(s):

Presently seeing:.....

Previously seen:.....

.....

Community Nurse ☐

Name(s):

Presently seeing:.....

Previously seen:.....

.....

Speech Therapist ☐

Name(s):

Presently seeing:.....

Previously seen:.....

.....

- 13 Who was the **most** helpful professional you have worked with (past or present) from the above list ?

Name:.....

- 14 Who was the **least** helpful professional you have worked with (past or present) from the above list ?

Name:.....

- 15 How frequently do you *presently* have contact with any of the above professional services?

I see a professional more than once a week ☐  
Once a week ☐  
Once a fortnight ☐  
Once a month ☐  
Once every 3 months ☐  
About once a year ☐  
Never ☐



# Appendix 18

## MOST helpful Professional questionnaire continued

Instructions:

The following questions are about the kind of things professional helpers may do and your opinions about services you have received. Please circle the appropriate number for each question:

1= Always true	2= Often true	3= Hardly ever true	4= Never true
----------------	---------------	---------------------	---------------

If you don't understand or can't rate any item circle 'don't know'.

The most helpful professional:		always true	often true	hardly ever true	never true	
1.	Was courteous.	1	2	3	4	Don't know
2.	Explained clearly what I needed to do to help my child.	1	2	3	4	Don't know
3.	Suggested that my skills as a parent contributed to my child's problems.	1	2	3	4	Don't know
4.	Understood what I have been going through.	1	2	3	4	Don't know
5.	Treated me like an expert about my own child.	1	2	3	4	Don't know
6.	Took time to answer my questions or listen to my ideas.	1	2	3	4	Don't know
7.	Did <b>not</b> involve me in important decisions concerning my child's treatment.	1	2	3	4	Don't know
8.	Provided services that did <b>not</b> help.	1	2	3	4	Don't know
9.	Valued my opinion about my child.	1	2	3	4	Don't know
10.	Blamed me for my child's problem.	1	2	3	4	Don't know
11.	Did not seem to know very much about my child's problem.	1	2	3	4	Don't know
12.	Provided services which helped my child.	1	2	3	4	Don't know
13.	Indicated to me that I was doing my best for my child.	1	2	3	4	Don't know
14.	Cared about how I felt.	1	2	3	4	Don't know
15.	Was honest and up-front with me.	1	2	3	4	Don't know
16.	Implied that my emotions were harming my child.	1	2	3	4	Don't know
Did the professional helper do any of the following?				Yes	No	Unsure
17.	Help me make decisions about treatment			Yes	No	Unsure
18.	Help me find other services when he/she could not help.			Yes	No	Unsure
19.	Refuse to provide reasonable access to records I asked to see.			Yes	No	Unsure
20.	Give me accurate information about how services would help my child.			Yes	No	Unsure
21.	Continue to provide services even when they were no longer helpful.			Yes	No	Unsure

## **Appendix 19**

## THE HELPING BEHAVIOR CHECKLIST

**Instructions:** This questionnaire is about the kinds of things professional helpers may do and your opinions about services you have received. Decide if these statements are true of the helper being rated. Indicate your choice by placing an "X" in the brackets under your choice. Try to rate each statement. If you don't understand or can't rate any item, check the column "Don't Know."

### *The professional helper:*

	1 Almost Always True	2 Often True	3 Seldom True	4 Almost Never True	5 Don't Know
1) Was courteous.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2) Explained clearly what I needed to do to help my child.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3) Suggested that my skills as a parent contributed to my child's problem.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4) Understood what I have been going through.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5) Treated me like an expert about my own child.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6) Took time to answer my questions or listen to my ideas.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7) Didn't involve me in important decisions concerning my child's services...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8) Provided services that didn't help.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9) Valued my opinion about my child.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10) Blamed me for my child's problem.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11) Didn't seem to know very much about my child's problem. ....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12) Provided services which helped my child. ....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13) Indicated to me that I was doing my best for my child.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14) Cared about how I felt.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15) Was honest and up-front with me.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Did the professional helper ever do any of the following:*

	1	0	
	Yes	No	Unsure
X 17) Describe costs and payment plans clearly and accurately? .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
X 18) Inform me about risks associated with services?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
X 19) Bill me for services that I thought had not been provided?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
✓ 20) Help me make decisions about treatment?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
✓ 21) Help me find other services when he/she couldn't help?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
✓ 22) Refuse to provide reasonable access to records I asked to see?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
X 23) Do something that harmed my child?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
X 24) Discriminate against me because of my race, culture, religious beliefs, or sexual orientation?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
X 25) Encourage me to purchase unneeded goods or services in which he/she had a financial interest?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
✓ 26) Give me accurate information about how services would help my child?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
X 27) Charge more than I could afford?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
X 28) Give information about my child or me to someone without my permission?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
X 29) Encourage me to enter into a sexual relationship with him/her?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
X 30) Refuse to serve my child when I complained about something?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Appendix 20

Please complete one questionnaire below for the MOST and one for the LEAST helpful professional you have had contact with. If you have only had contact with one professional please just use the most helpful questionnaire below and tick 'only' here: ONLY ☐.

### MOST helpful Professional questionnaire (questionnaire 2)

1. Name of professional (i.e. answer to qu. 13 above): .....
2. Profession:
 

Clinical Psychologist	<input type="checkbox"/>
Educational Psychologist	<input type="checkbox"/>
Paediatrician	<input type="checkbox"/>
Psychiatrist	<input type="checkbox"/>
Social worker	<input type="checkbox"/>
Occupational Therapist	<input type="checkbox"/>
Health Visitor	<input type="checkbox"/>
Community Nurse	<input type="checkbox"/>
Speech therapist	<input type="checkbox"/>
3. Approximate date of initial contact:
4. Is contact ongoing?
 

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
5. About how many months did this helper provide services to you or your child?
 

Months:	
---------	--
6. Was it made clear to you exactly why you were seeing this professional as opposed to a member of a different profession?
 

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
7. Approximate total number of contacts with this professional:
 

1	<input type="checkbox"/>
2-5	<input type="checkbox"/>
5-8	<input type="checkbox"/>
8-11	<input type="checkbox"/>
12-15	<input type="checkbox"/>
15-18	<input type="checkbox"/>
19 plus	<input type="checkbox"/>
8. What was the problem that caused you to bring your child to this professional helper?
9. Was your child aware of this professionals involvement?
 

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
10. Was your child satisfied with the professional?
 

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
Somewhat	<input type="checkbox"/>

## **Appendix 21**

# PARENTING STRESS INDEX

## (Short Form)

Richard R. Abidin  
University of Virginia

---

### Directions:

In answering the following questions, please think about the child you are most concerned about.

The questions on the following pages ask you to mark an answer which best describes your feelings. While you may not find an answer which exactly states your feelings, please mark the answer which comes closest to describing how you feel.

YOUR FIRST REACTION TO EACH QUESTION SHOULD BE YOUR ANSWER.

Please mark the degree to which you agree or disagree with the following statements by circling the number which best matches how you feel. If you are not sure, please circle #3.

1	2	3	4	5
Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree

### Example:

I enjoy going to the movies. (If you sometimes enjoy going to the movies, you would circle #2.)

1   2   3   4   5

---

**PAR** Psychological Assessment Resources, Inc.  
P.O. Box 998/Odessa, Florida 33556/Toll-Free 1-800-331-TEST

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Reorder #RO-1698

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1	2	3	4	5
Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree

- |  |                         |   |   |   |   |
|--|-------------------------|---|---|---|---|
| 1. I often have the feeling that I cannot handle things very well.   | 1                       | 2 | 3 | 4 | 5 |
| 2. I find myself giving up more of my life to meet my children's needs than I ever expected.                       | 1                       | 2 | 3 | 4 | 5 |
| 3. I feel trapped by my responsibilities as a parent.  | 1                       | 2 | 3 | 4 | 5 |
| 4. Since having this child I have been unable to do new and different things.                                      | 1                       | 2 | 3 | 4 | 5 |
| 5. Since having a child I feel that I am almost never able to do things that I like to do.                         | 1                       | 2 | 3 | 4 | 5 |
| 6. I am unhappy with the last purchase of clothing I made for myself.  | 1                       | 2 | 3 | 4 | 5 |
| 7. There are quite a few things that bother me about my life.  | 1                       | 2 | 3 | 4 | 5 |
| 8. Having a child has caused more problems than I expected in my relationship with my spouse (male/female friend). | 1                       | 2 | 3 | 4 | 5 |
| 9. I feel alone and without friends.   | 1                       | 2 | 3 | 4 | 5 |
| 10. When I go to a party I usually expect not to enjoy myself.   | 1                       | 2 | 3 | 4 | 5 |
| 11. I am not as interested in people as I used to be.  | 1                       | 2 | 3 | 4 | 5 |
| 12. I don't enjoy things as I used to.   | 1                       | 2 | 3 | 4 | 5 |
|  | PD <input type="text"/> |   |   |   |   |
| 13. My child rarely does things for me that make me feel good.   | 1                       | 2 | 3 | 4 | 5 |
| 14. Most times I feel that my child does not like me and does not want to be close to me.                          | 1                       | 2 | 3 | 4 | 5 |
| 15. My child smiles at me much less than I expected.   | 1                       | 2 | 3 | 4 | 5 |
| 16. When I do things for my child I get the feeling that my efforts are not appreciated very much.                 | 1                       | 2 | 3 | 4 | 5 |
| 17. When playing, my child doesn't often giggle or laugh.  | 1                       | 2 | 3 | 4 | 5 |
| 18. My child doesn't seem to learn as quickly as most children.  | 1                       | 2 | 3 | 4 | 5 |
| 19. My child doesn't seem to smile as much as most children.   | 1                       | 2 | 3 | 4 | 5 |
| 20. My child is not able to do as much as I expected.  | 1                       | 2 | 3 | 4 | 5 |
| 21. It takes a long time and it is very hard for my child to get used to new things.                               | 1                       | 2 | 3 | 4 | 5 |



1	2	3	4	5
Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree

22. I feel that I am:
1. not very good at being a parent,
  2. a person who has some trouble being a parent,
  3. an average parent,
  4. a better than average parent,
  5. a very good parent.

1 2 3 4 5

23. I expected to have closer and warmer feelings for my child than I do and he bothers me.

1 2 3 4 5

24. Sometimes my child does things that bother me just to be mean.

1 2 3 4 5

P-C DI

25. My child seems to cry or fuss more often than most children.

1 2 3 4 5

26. My child generally wakes up in a bad mood.

1 2 3 4 5

27. I feel that my child is very moody and easily upset.

1 2 3 4 5

28. My child does a few things which bother me a great deal.

1 2 3 4 5

29. My child reacts very strongly when something happens that my child doesn't like.

1 2 3 4 5

30. My child gets upset easily over the smallest thing.

1 2 3 4 5

31. My child's sleeping or eating schedule was much harder to establish than I expected.

1 2 3 4 5

32. I have found that getting my child to do something or stop doing something is:
1. much harder than I expected,
  2. somewhat harder than I expected,
  3. about as hard as I expected,
  4. somewhat easier than I expected,
  5. much easier than I expected.

1 2 3 4 5

33. Think carefully and count the number of things which your child does that bother you. For example: dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc. Please circle the number which includes the number of things you counted.

1. 10+

2. 8-9

3. 6-7

4. 4-5

5. 1-3

1 2 3 4 5

34. There are some things my child does that really bother me a lot.

1 2 3 4 5

35. My child turned out to be more of a problem than I had expected.

1 2 3 4 5

36. My child makes more demands on me than most children.

1 2 3 4 5

D.C.

## **Appendix 22**

# ABERRANT BEHAVIOUR CHECK-LIST COMMUNITY INSTRUCTIONS

The ABC-Community rating scale is designed to be used with clients living in the community. Please note that the term *client* is used throughout to refer to the person being rated. This may be a child of school age, an adolescent, or an adult.

Please rate this client's behavior for the last four weeks. For each item, decide whether the behavior is a problem and circle the appropriate number:

- 0 = not at all a problem
- 1 = the behavior is a problem but slight in degree
- 2 = the problem is moderately serious
- 3 = the problem is severe in degree

When judging this client's behavior, please keep the following points in mind:

- (a) Take relative *frequency* into account for each behavior specified. For example if the client averages more temper outbursts than most other clients you know or most others in his/her class, it is probably moderately serious (2) or severe (3) even if these occur only once or twice a week. Other behaviors, such as noncompliance, would probably have to occur more frequently to merit an extreme rating.
- (b) If you have access to this information, consider the experiences of other care providers with this client. If the client has problems with others but not with you, try to take the whole picture into account.
- (c) Try to consider whether a given behavior interferes with his/her *development, functioning, or relationships*. For example, body rocking or social withdrawal may not disrupt other children or adults, but it almost certainly hinders individual development or functioning.

*Do not spend too much time on each item — your first reaction is usually the right one.*

1. Excessively active at home, school, work, or elsewhere	0	1	2	3
2. Injures self on purpose	0	1	2	3
3. Listless, sluggish, inactive	0	1	2	3
4. Aggressive to other children or adults (verbally or physically)	0	1	2	3
5. Seeks isolation from others	0	1	2	3
6. Meaningless, recurring body movements	0	1	2	3
7. Boisterous (inappropriately noisy and rough)	0	1	2	3
8. Screams inappropriately	0	1	2	3
9. Talks excessively	0	1	2	3
10. Temper tantrums/outbursts	0	1	2	3
<hr/>				
11. Stereotyped behavior; abnormal, repetitive movements	0	1	2	3
12. Preoccupied; stares into space	0	1	2	3
13. Impulsive (acts without thinking)	0	1	2	3
14. Irritable and whiny	0	1	2	3
15. Restless, unable to sit still	0	1	2	3
16. Withdrawn; prefers solitary activities	0	1	2	3
17. Odd, bizarre in behavior	0	1	2	3
18. Disobedient; difficult to control	0	1	2	3
19. Yells at inappropriate times	0	1	2	3
20. Fixed facial expression; lacks emotional responsiveness	0	1	2	3

21. Disturbs others	0	1	2	3
22. Repetitive speech	0	1	2	3
23. Does nothing but sit and watch others	0	1	2	3
24. Uncooperative	0	1	2	3
25. Depressed mood	0	1	2	3
26. Resists any form of physical contact	0*	1	2	3
27. Moves or rolls head back and forth repetitively	0	1	2	3
28. Does not pay attention to instructions	0	1	2	3
29. Demands must be met immediately	0	1	2	3
30. Isolates himself/herself from other children or adults	0	1	2	3
<hr/>				
31. Disrupts group activities	0	1	2	3
32. Sits or stands in one position for a long time	0	1	2	3
33. Talks to self loudly	0	1	2	3
34. Cries over minor annoyances and hurts	0	1	2	3
35. Repetitive hand, body, or head movements	0	1	2	3
36. Mood changes quickly	0	1	2	3
37. Unresponsive to structured activities (does not react)	0	1	2	3
38. Does not stay in seat (e.g., during lesson or training periods, meals, etc.)	0	1	2	3
39. Will not sit still for any length of time	0	1	2	3
40. Is difficult to reach, contact, or get through to	0	1	2	3
<hr/>				
41. Cries and screams inappropriately	0	1	2	3
42. Prefers to be alone	0	1	2	3
43. Does not try to communicate by words or gestures	0	1	2	3
44. Easily distractible	0	1	2	3
45. Waves or shakes the extremities repeatedly	0	1	2	3
46. Repeats a word or phrase over and over	0	1	2	3
47. Stamps feet or bangs objects or slams doors	0	1	2	3
48. Constantly runs or jumps around the room	0	1	2	3
49. Rocks body back and forth repeatedly	0	1	2	3
50. Deliberately hurts himself/herself	0	1	2	3
<hr/>				
51. Pays no attention when spoken to	0	1	2	3
52. Does physical violence to self	0	1	2	3
53. Inactive, never moves spontaneously	0	1	2	3
54. Tends to be excessively active	0	1	2	3
55. Responds negatively to affection	0	1	2	3
56. Deliberately ignores directions	0	1	2	3
57. Has temper outbursts or tantrums when he/she does not get own way	0	1	2	3
58. Shows few social reactions to others	0	1	2	3

THANK YOU FOR YOUR TIME. PLEASE NOW RETURN THE QUESTIONNAIRE IN THE S.A.E. PROVIDED.

## **Appendix 23**

# FAMILY SUPPORT SCALE (FSS)

## (ADAPTED FROM DUNST, JENKINS AND TRIVETTE)

Listed below are sources of support that are often helpful to members of families raising a young child. This questionnaire asks you to indicate how helpful each source is to *your family*.

Please *circle* the response that best describes how helpful the sources have been to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, circle the NA (not available) response.

1. My parents
2. My partner/spouse's parents
3. My relatives/kin
4. My partner/spouse's relatives/kin
5. Partner/spouse
6. My friends
7. My partner/spouse's friends
8. My own children
9. Other parents
10. Co-workers
11. Parent groups
12. Social groups/clubs
13. Place of worship/religious organization
14. My family or child's doctor
15. Professional helpers (social workers, therapists, teachers, etc.)
16. Professional agencies (public health, social services, mental health, etc)
17. School/day-care centre
18. Early intervention programme
19. \_\_\_\_\_
20. \_\_\_\_\_

	Not available	Not helpful at all	Sometimes helpful	Generally helpful	Very helpful	Extremely helpful
1. My parents	NA	1	2	3	4	5
2. My partner/spouse's parents	NA	1	2	3	4	5
3. My relatives/kin	NA	1	2	3	4	5
4. My partner/spouse's relatives/kin	NA	1	2	3	4	5
5. Partner/spouse	NA	1	2	3	4	5
6. My friends	NA	1	2	3	4	5
7. My partner/spouse's friends	NA	1	2	3	4	5
8. My own children	NA	1	2	3	4	5
9. Other parents	NA	1	2	3	4	5
10. Co-workers	NA	1	2	3	4	5
11. Parent groups	NA	1	2	3	4	5
12. Social groups/clubs	NA	1	2	3	4	5
13. Place of worship/religious organization	NA	1	2	3	4	5
14. My family or child's doctor	NA	1	2	3	4	5
15. Professional helpers (social workers, therapists, teachers, etc.)	NA	1	2	3	4	5
16. Professional agencies (public health, social services, mental health, etc)	NA	1	2	3	4	5
17. School/day-care centre	NA	1	2	3	4	5
18. Early intervention programme	NA	1	2	3	4	5
19. _____	NA	1	2	3	4	5
20. _____	NA	1	2	3	4	5



© 1993, Dunst, Trivette and Hamby. *Family Support Scale* by Carl J. Dunst, Carol M. Trivette and Deborah Hamby from Dunst, C. J., Trivette, C. M. and Deal, A. G. (Eds) (1994). *Supporting and Strengthening Families: Volume 1: Methods, Strategies and Practices*. Reproduced by kind permission of the authors and published by Brookline Books, Cambridge, MA.

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## Appendix 24

### PROFESSIONALS' BELIEFS ABOUT PARENTS- ADAPTED

Research ID no.:

Please tick the box that best describes your view.

		Strongly Agree	Agree	Disagree	Strongly Disagree
1	Parents of children who receive services in relation to their child's learning difficulties are usually too emotionally involved to report their children's behaviour accurately	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	It is usually advisable to give parents unlimited access to a child's records	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	It is not often advisable to tell parents explicitly what to do to help their child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	Parents of child with learning difficulties usually are not doing their best for their child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	Parents are rarely experts about their child with learning difficulties unless they have had professional training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	For many children with learning difficulties medication is necessary	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	The most frequent cause of severe emotional disturbance in children with learning difficulties is parenting behavior	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	Letting parents see a child's records makes an institution vulnerable to being sued	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	In health work with children with learning difficulties, practitioners need current research-based knowledge about learning difficulty conditions of children and adolescents.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	Family dynamics are usually the major cause of children with learning difficulties emotional difficulties.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11	When a child with a learning difficulty is referred for disturbed behavior, he or she is likely to be the identified patient in a dysfunctional family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	Parents are experts about their own children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13	It is often harmful to share information about the causes of a child's learning difficulty with parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14	Most parents of children with learning difficulties are doing their best for their child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	The most frequent cause of emotional difficulties in children with learning difficulties is emotional dysfunction in the parents.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16	Drugs are often helpful in treating children with learning difficulties	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



17	It is rarely necessary for me to refer families with a child learning difficulties to professionals in other disciplines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18	It is therapeutically sound to tell parents directly what they should do to help their child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19	Psychotropic medication should almost never be used with children with learning difficulties until psychosocial interventions have been tried for a few months	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20	Professionals should almost always be honest and up-front with parents.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21	It is seldom damaging to parents to tell them the likely causes of their learning difficulty.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22	Parents' views about their child with a learning difficulty are important mostly to give the worker clues about family dynamics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23	The most frequent cause of disturbed behavior in a child with learning difficulties is poor parenting skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24	Parents have expertise that professionals do not have	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25	Problems/needs in children with learning difficulties can usually be traced to pathological parenting.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26	All parents should be told the specific ways treatment is expected to help their child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27	Parents of a child with learning difficulties often can teach professionals what responses are helpful to their child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28	Professionals should share just about everything they know about a learning disability with parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29	Medical journals are a good source of information about learning difficulties	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30	Family dysfunction is often a reaction to a child's biologically based difficult behavior	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

PLEASE CONTINUE



DEMOGRAPHIC INFORMATION  
(please tick answers that apply)

31. YOUR DISCIPLINE

- |                                 |                          |
|---------------------------------|--------------------------|
| 1 Social worker                 | <input type="checkbox"/> |
| 2 Clinical Psychologist         | <input type="checkbox"/> |
| 3 Occupational Therapist        | <input type="checkbox"/> |
| 4 Community Nurse               | <input type="checkbox"/> |
| 5 Psychiatrist                  | <input type="checkbox"/> |
| 6 Speech and Language Therapist | <input type="checkbox"/> |
| 7 Paediatrician                 | <input type="checkbox"/> |
| 8 Educational Psychologist      | <input type="checkbox"/> |
| 9. Dietician                    | <input type="checkbox"/> |
| 10 Health Visitor               | <input type="checkbox"/> |

Other (please specify): .....

32. Number of YEARS IN PRACTICE \_\_\_\_\_

33. PREDOMINANT ORIENTATION (circle no more than 2):

- |                                   |                          |
|-----------------------------------|--------------------------|
| 1 Psychodynamic/Ego Psychological | <input type="checkbox"/> |
| 2 Family systems                  | <input type="checkbox"/> |
| 3 Cognitive/Behavioral            | <input type="checkbox"/> |
| 4 Neuropsychological              | <input type="checkbox"/> |
| 5 Existential/Humanistic          | <input type="checkbox"/> |
| 6. Medical                        | <input type="checkbox"/> |
| 7 Other (please specify):         |                          |

34. Your AGE \_\_\_\_\_

35. GENDER

- |        |                          |
|--------|--------------------------|
| Female | <input type="checkbox"/> |
| Male   | <input type="checkbox"/> |

36. Please tick your frequency of contact with parents of children with learning difficulties (i.e. aged 19 and below). I have:

- |  |                          |
|--|--------------------------|
| <b>Regular</b> contact with parents of children with learning difficulties.      | <input type="checkbox"/> |
| <b>Intermittent</b> contact with parents of children with learning difficulties. | <input type="checkbox"/> |
| <b>Very little</b> contact with parents of children with learning difficulties.  | <input type="checkbox"/> |
| <b>No</b> contact with parents of children with learning difficulties.           | <input type="checkbox"/> |

**Please feel free to add any comments regarding your beliefs about parents or regarding this questionnaire below and /or overleaf.**

Thank you for your time.

## Appendix 25

### PROVIDERS' BELIEFS ABOUT PARENTS

Research ID no.:

Please mark the box that best describes your view.

		Strongly Agree	Agree	Disagree	Strongly Disagree
1	Parents of children who need mental health services are usually too emotionally involved to report their children's behavior accurately.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	It is usually advisable to give parents unlimited access to a child's records	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	It is seldom advisable to tell parents explicitly what to do to help their child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	Parents of an emotionally disturbed child usually are not doing their best for their child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	Clients should routinely be advised about potential risks of service or treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Parents are seldom experts about their children unless they have had professional training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	For many psychiatric disorders in children and adolescents, medication is necessary.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	The most frequent cause of severe emotional disturbance in children is parenting behavior.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	Letting parents see a child's records makes an institution vulnerable to being sued.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	. In mental health work with children, practitioners need current research-based knowledge about psychopathological conditions of children and adolescents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11	Apprising clients about risks of service is undesirable because it generates anxiety unnecessarily	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	Family dynamics are usually the major cause of children's emotional disorders.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13	When a child is referred for disturbed behavior, he or she is likely to be the identified patient in a dysfunctional family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14	Parents are experts about their own children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	It is often harmful to share information about the causes of a child's disturbance with parents.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16	Most parents of emotionally disturbed children are doing their best for their child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17	. The most frequent cause of emotional problems in children is emotional in the parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18	Drugs are often helpful in treating emotional disorders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

19	It is rarely necessary for me to refer families with an emotionally disturbed to professionals in other disciplines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20	It is therapeutically sound to tell parents directly what they should do to help their child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21	Psychotropic medication should almost never be used with children until psychosocial interventions have been tried for a few months.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22	Mental health professionals should almost always be honest and up-front with parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23	It is seldom damaging to parents to tell them the likely causes of their child's emotional problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24	Parents' views about their emotionally disturbed child are important mostly to give the worker clues about family dynamics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25	Clients should routinely be informed about the costs and payment plans for service.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26	The most frequent cause of disturbed behavior in a child is poor parenting skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27	Parents have expertise that mental health professionals do not have	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28	Psychiatric problems in children can usually be traced to pathological parenting.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29	All parents should be told the specific ways treatment is expected to help their child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30	Parents of an emotionally disturbed child often can teach professionals what responses are helpful to their child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31	Professionals should share just about everything they know about a child's psychiatric disorder with parents				
32	Medical journals are a good source of information about emotional disorders.				
33	Family dysfunction is often a reaction to a child's biologically based difficult behavior				

## Appendix 26

### Parents' Beliefs about Parents Questionnaire (Questionnaire 4)

Please tick your choice regarding the following statements:

		Strongly Agree	Agree	Disagree	Strongly Disagree
1.	Parents of children who receive services in relation to their child's special needs are usually too emotionally involved to report their children's behaviour accurately.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	It is usually advisable to give parents unlimited access to a child's records.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	It is hardly ever advisable to tell parents explicitly what to do to help their child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	Parents are hardly ever experts about their child with special needs unless they have had professional training.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	For many children with special needs medication is necessary.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	The most frequent cause of severe emotional disturbance in children with special needs is parenting behavior.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	Family dynamics are usually the major cause of children with special needs' emotional problems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	Parents are experts about their own children.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.	The most frequent cause of emotional problems in children with special needs is emotional dysfunction in the parents.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	Drugs are often helpful in treating children with special needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11.	It is therapeutically sound for professionals to tell parents directly what they should do to help their child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12.	Medication should almost never be used with children with special needs until psychosocial interventions have been tried for a few months.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13.	Professionals should almost always be honest and up-front with parents.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14.	The most frequent cause of disturbed behavior in a child with special needs is poor parenting skills.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15.	Parents have expertise that professionals do not have.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16.	Problems in children with special needs can usually be traced to bad parenting.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17.	All parents should be told the specific ways treatment is expected to help their child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18.	Parents of a child with special needs often can teach professionals what responses are helpful to their child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19.	Professionals should share just about everything they know about a child's special needs with parents.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20.	Most parents of children with special needs are doing their best for their child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## **Appendix 27**

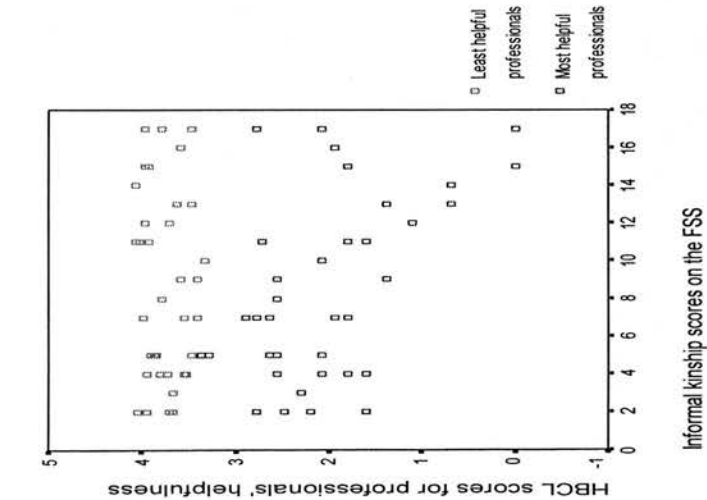


Figure 5, Scatter plot of HBCL-A scores for most and least helpful professionals by the informal kinship support scale on the FSS.

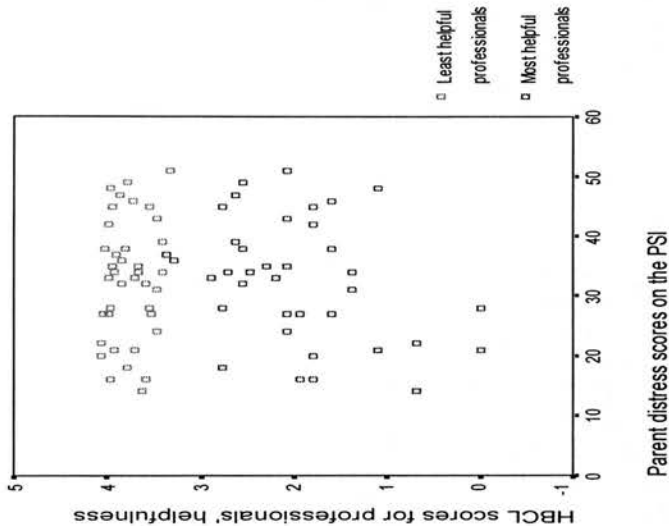


Figure 6, Scatter plot of HBCL-A scores for most and least helpful professionals by the parents distress scale on the PSI.

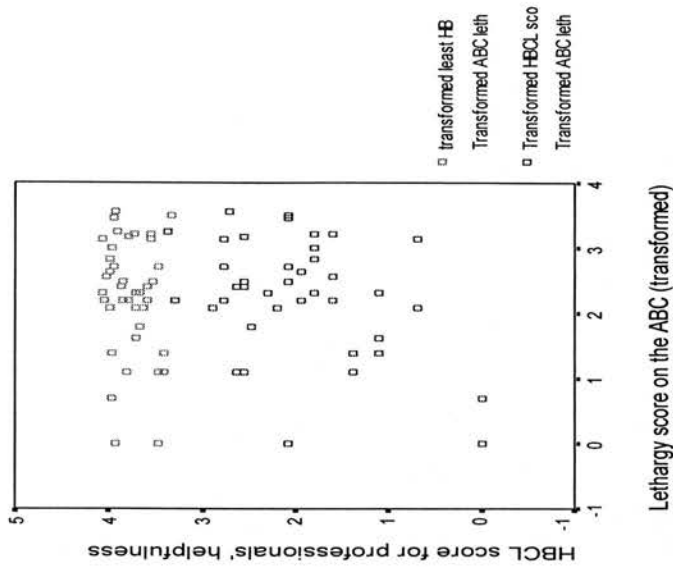


Figure 7, Scatter plot of HBCL-A scores for most and least helpful professionals by the child's lethargy/withdrawal scale on the ABC.

## Appendix 28

ANCOVAs were carried out first with parents' ratings of the most helpful professional on the HBCL-A as the dependent variable. Separate ANCOVAs were carried out for each factor on the PBAP-A. PBAP-A factors were entered into analysis as a random factor. Separate ANCOVAs were also carried out for each covariate. The factors that correlated most strongly with HBCL-A scores from each scale were entered as the covariates.

ANCOVA was then carried out with parents' ratings of the least helpful professional on the HBCL-A as the dependent variable. After adjusting for parents beliefs about parents on the validate factor, no significant effect was found between professionals' beliefs about parents on the PBAP-A and HBCL-A scores for least helpful professionals

### *Summary*

Results indicate that professionals' beliefs about parents do not appear to influence parents' perceptions of the helpfulness of professionals on the HBCL-A. However, this result is based upon a small sample size.

## **Appendix 29**

### **Correlation matrix**



### Correlations

		Transformed HBCL score for professionals named as most helpful.	Transformed HBCL score for professionals named as least helpful.	Age of the individual completing the questionn aire.	Is at least one member of the family in employment?	Marital status	Child's age	Child's gender
Transformed HBCL score for professionals named as most helpful.	Pearson Correlation Sig. (2-tailed) N	1.000 .46	-.106 .520 39	-.357* .015 46	.248 .097 46	-.018 .904 46	-.267 .073 46	-.241 .107 46
Transformed HBCL score for professionals named as least helpful.	Pearson Correlation Sig. (2-tailed) N	-.106 .520 39	1.000 .876 39	.026 .876 39	.047 .774 39	-.235 .150 39	.038 .820 39	-.091 .582 39
Age of the individual completing the questionnaire.	Pearson Correlation Sig. (2-tailed) N	-.357* .015 46	.026 .876 39	1.000 .539 46	.093 .539 46	-.090 .550 46	.323* .028 46	.149 .324 46
Is at least one member of the family in employment?	Pearson Correlation Sig. (2-tailed) N	.248 .097 46	.047 .774 39	.093 .539 46	1.000 .000 46	-.606** .000 46	.078 .608 46	-.053 .727 46
Marital status	Pearson Correlation Sig. (2-tailed) N	-.018 .904 46	-.235 .150 39	-.090 .550 46	-.606** .000 46	1.000 .930 46	.013 .930 46	.043 .776 46
Child's age	Pearson Correlation Sig. (2-tailed) N	-.267 .073 46	.038 .820 39	.323* .028 46	.078 .608 46	.013 .930 46	1.000 .466 46	.110 .466 46
Child's gender	Pearson Correlation Sig. (2-tailed) N	-.241 .107 46	-.091 .582 39	.149 .324 46	-.053 .727 46	.043 .776 46	.110 .466 46	1.000 .466 46
Matched most helpful professional's BLAME score	Pearson Correlation Sig. (2-tailed) N	.037 .839 33	.065 .736 29	.285 .107 33	.278 .117 33	-.366* .036 33	.201 .263 33	-.096 .596 33

### Correlations

		Transformed HBCL score for professionals named as most helpful.	Transformed HBCL score for professionals named as least helpful.	Age of the individual completing the questionn aire.	Is at least one member of the family in employment?	Marital status	Child's age	Child's gender
Matched most helpful professional's INFORM score	Pearson Correlation Sig. (2-tailed) N	-.089 .620 33	-.053 .786 29	.096 .594 33	.190 .290 33	-.192 .286 33	.182 .311 33	-.247 .165 33
Matched most helpful professional's VALIDATE score	Pearson Correlation Sig. (2-tailed) N	-.123 .494 33	.086 .657 29	.256 .151 33	.222 .214 33	-.243 .173 33	.168 .351 33	-.151 .403 33
Matched most helpful professional's INSTRUCT score	Pearson Correlation Sig. (2-tailed) N	-.263 .140 33	.185 .336 29	.036 .844 33	-.153 .395 33	.189 .292 33	.067 .710 33	-.029 .874 33
Matched Least helpful professional's BLAME score	Pearson Correlation Sig. (2-tailed) N	.176 .566 13	-.286 .343 13	-.156 .610 13	-.295 .327 13	.766** .002 13	.099 .746 13	.253 .404 13
Matched Least helpful professional's INFORM score	Pearson Correlation Sig. (2-tailed) N	-.159 .603 13	.255 .401 13	.129 .675 13	.308 .306 13	.337 .260 13	.337 .260 13	.437 .136 13
Matched Least helpful professiona's VALIDATE score	Pearson Correlation Sig. (2-tailed) N	.038 .902 13	-.084 .785 13	-.187 .540 13	.025 .937 13	.453 .120 13	.175 .568 13	.104 .735 13
Matched Least helpful professionals INSTRUCT score	Pearson Correlation Sig. (2-tailed) N	-.476 .100 13	-.001 .998 13	.151 .621 13	.192 .529 13	-.568* .043 13	.120 .695 13	-.058 .851 13
Is contact ongoing with the most helpful professional?	Pearson Correlation Sig. (2-tailed) N	.037 .809 46	.192 .242 39	.148 .326 46	-.086 .568 46	.045 .769 46	.238 .112 46	.120 .429 46
Is contact ongoing with the least helpful professional?	Pearson Correlation Sig. (2-tailed) N	-.185 .248 41	.036 .830 39	.098 .540 41	-.135 .399 41	.158 .323 41	.380* .014 41	.003 .986 41

### Correlations

		Transformed HBCL score for professionals named as most helpful.	Transformed HBCL score for professionals named as least helpful.	Age of the individual completing the questionn aire.	Is at least one member of the family in employment?	Marital status	Child's age	Child's gender
Number of contacts with most helpful professional.	Pearson Correlation	-.121	.003	.205	-.051	.109	.059	.219
	Sig. (2-tailed)	.428	.986	.178	.738	.474	.701	.149
	N	45	39	45	45	45	45	45
Number of contacts with least helpful professional.	Pearson Correlation	.273	.085	-.118	.073	-.167	-.097	.149
	Sig. (2-tailed)	.093	.612	.474	.657	.309	.557	.366
	N	39	38	39	39	39	39	39
Length of contact with most helpful professional in months.	Pearson Correlation	-.028	-.242	.094	-.212	.057	-.067	-.006
	Sig. (2-tailed)	.859	.149	.550	.172	.714	.667	.970
	N	43	37	43	43	43	43	43
Length of contact with least helpful professional in months.	Pearson Correlation	-.069	-.044	-.062	-.041	-.066	-.031	-.004
	Sig. (2-tailed)	.685	.799	.715	.811	.698	.856	.982
	N	37	36	37	37	37	37	37
Parent's understanding of most helpful professional role.	Pearson Correlation	.240	.171	-.092	-.193	.157	-.232	-.166
	Sig. (2-tailed)	.108	.297	.543	.199	.298	.120	.271
	N	46	39	46	46	46	46	46
Parent's understanding of least helpful professional role.	Pearson Correlation	-.323*	.198	.160	.169	-.201	.123	-.089
	Sig. (2-tailed)	.042	.227	.324	.297	.214	.451	.583
	N	40	39	40	40	40	40	40
Parents' beliefs about parents on the blame factor.	Pearson Correlation	-.140	-.257	.221	.083	.105	.171	.277
	Sig. (2-tailed)	.354	.114	.139	.584	.488	.256	.063
	N	46	39	46	46	46	46	46
Parents' beliefs about parents on the inform factor: transformed.	Pearson Correlation	.211	-.039	.126	.069	.022	-.018	.174
	Sig. (2-tailed)	.159	.813	.404	.649	.883	.904	.247
	N	46	39	46	46	46	46	46
Parents' beliefs about parents on the validate factor.	Pearson Correlation	.211	-.339*	.100	.222	-.099	.217	.131
	Sig. (2-tailed)	.159	.035	.508	.138	.512	.148	.385
	N	46	39	46	46	46	46	46

### Correlations

		Transformed HBCL score for professionals named as most helpful.	Transformed HBCL score for professionals named as least helpful.	Age of the individual completing the questionn aire.	Is at least one member of the family in employment?	Marital status	Child's age	Child's gender
Parents' beliefs about parents on the instruct factor: transformed.	Pearson Correlation Sig. (2-tailed) N	.085 .573 46	.108 .515 39	.129 .393 46	.174 .248 46	-.086 .570 46	.180 .232 46	.233 .119 46
Partner/spouse helpfulness on FSS.	Pearson Correlation Sig. (2-tailed) N	-.026 .865 45	-.170 .302 39	-.301* .045 45	-.517** .000 45	.611** .000 45	-.141 .356 45	-.123 .421 45
Informal kinship support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.512** .000 45	.011 .947 39	.091 .552 45	-.319* .033 45	.161 .290 45	.131 .390 45	.132 .389 45
Formal kinship support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.201 .186 45	-.123 .454 39	-.342* .021 45	-.324* .030 45	.030 .845 45	-.273 .070 45	.022 .886 45
Social organisations support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.322* .031 45	.034 .836 39	.040 .794 45	-.245 .104 45	.042 .785 45	.112 .466 45	-.101 .508 45
Professional services support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.258 .087 45	-.125 .447 39	-.197 .194 45	-.188 .217 45	.078 .610 45	-.148 .333 45	-.234 .122 45
Total support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.385** .009 45	-.091 .582 39	-.162 .286 45	-.440** .002 45	.261 .083 45	-.056 .716 45	-.076 .619 45
Parent distress score on PSI.	Pearson Correlation Sig. (2-tailed) N	.410** .005 46	-.106 .519 39	.062 .682 46	.114 .452 46	.070 .644 46	-.169 .261 46	-.134 .373 46
Parent - child dysfunctional interaction score on PSI.	Pearson Correlation Sig. (2-tailed) N	.329* .025 46	-.064 .698 39	-.048 .749 46	.192 .201 46	.086 .571 46	-.111 .464 46	-.376** .010 46

### Correlations

		Transformed HBCL score for professionals named as most helpful.	Transformed HBCL score for professionals named as least helpful.	Age of the individual completing the questionn aire.	Is at least one member of the family in employment?	Marital status	Child's age	Child's gender
Difficult child score on PSI.	Pearson Correlation	.202	-.181	-.039	.207	-.126	-.162	-.442**
	Sig. (2-tailed)	.178	.269	.796	.167	.404	.281	.002
	N	46	39	46	46	46	46	46
Total score on PSI.	Pearson Correlation	.362*	-.148	.003	.178	.032	-.170	-.345*
	Sig. (2-tailed)	.013	.367	.982	.236	.834	.258	.019
	N	46	39	46	46	46	46	46
Transformed ABC irritability factor	Pearson Correlation	.138	-.045	.093	.211	-.036	-.107	-.535**
	Sig. (2-tailed)	.360	.786	.541	.159	.812	.481	.000
	N	46	39	46	46	46	46	46
Transformed ABC lethargy factor.	Pearson Correlation	.493**	.160	-.010	.263	-.002	-.164	-.522**
	Sig. (2-tailed)	.000	.330	.949	.078	.991	.275	.000
	N	46	39	46	46	46	46	46
Transformed ABC stereotype factor	Pearson Correlation	.110	.107	.074	.122	.005	-.203	-.638**
	Sig. (2-tailed)	.466	.516	.626	.421	.974	.176	.000
	N	46	39	46	46	46	46	46
ABC hyperactivity factor	Pearson Correlation	.237	.017	.319*	.269	-.120	-.179	-.495**
	Sig. (2-tailed)	.112	.919	.031	.071	.425	.235	.000
	N	46	39	46	46	46	46	46
ABC inappropriate speech factor.	Pearson Correlation	.077	.046	.213	.274	-.269	.007	-.254
	Sig. (2-tailed)	.613	.781	.156	.065	.071	.961	.089
	N	46	39	46	46	46	46	46
Total score on ABC.	Pearson Correlation	.245	.018	.224	.295*	-.039	-.128	-.556**
	Sig. (2-tailed)	.101	.915	.134	.046	.795	.397	.000
	N	46	39	46	46	46	46	46

### Correlations

		Matched most helpful professional's BLAME score	Matched most helpful professional's INFORM score	Matched most helpful professional's VALIDATE score	Matched most helpful professional's INSTRUCT score	Matched Least helpful professional's BLAME score	Matched Least helpful professional's INFORM score
Transformed HBCL score for professionals named as most helpful.	Pearson Correlation	.037	-.089	-.123	-.263	.176	-.159
	Sig. (2-tailed)	.839	.620	.494	.140	.566	.603
	N	33	33	33	33	13	13
Transformed HBCL score for professionals named as least helpful.	Pearson Correlation	.065	-.053	.086	.185	-.286	.255
	Sig. (2-tailed)	.736	.786	.657	.336	.343	.401
	N	29	29	29	29	13	13
Age of the individual completing the questionnaire.	Pearson Correlation	.285	.096	.256	.036	-.156	.129
	Sig. (2-tailed)	.107	.594	.151	.844	.610	.675
	N	33	33	33	33	13	13
Is at least one member of the family in employment?	Pearson Correlation	.278	.190	.222	-.153	-.295	.308
	Sig. (2-tailed)	.117	.290	.214	.395	.327	.306
	N	33	33	33	33	13	13
Marital status	Pearson Correlation	-.366*	-.192	-.243	.189	.766**	.337
	Sig. (2-tailed)	.036	.286	.173	.292	.002	.260
	N	33	33	33	33	13	13
Child's age	Pearson Correlation	.201	.182	.168	.067	.099	.337
	Sig. (2-tailed)	.263	.311	.351	.710	.746	.260
	N	33	33	33	33	13	13
Child's gender	Pearson Correlation	-.096	-.247	-.151	-.029	.253	.437
	Sig. (2-tailed)	.596	.165	.403	.874	.404	.136
	N	33	33	33	33	13	13
Matched most helpful professional's BLAME score	Pearson Correlation	1.000	.339	.376*	-.134	-.179	.085
	Sig. (2-tailed)	.	.054	.031	.457	.621	.816
	N	33	33	33	33	10	10

### Correlations

		Matched most helpful professional's BLAME score	Matched most helpful professional's INFORM score	Matched most helpful professional's VALIDATE score	Matched most helpful professional's INSTRUCT score	Matched Least helpful professional's BLAME score	Matched Least helpful professional's INFORM score
Matched most helpful professional's INFORM score	Pearson Correlation Sig. (2-tailed) N	.339 .054 33	1.000 .000 33	.725** .000 33	.291 .100 33	-.591 .072 10	-.717* .020 10
Matched most helpful professional's VALIDATE score	Pearson Correlation Sig. (2-tailed) N	.376* .031 33	.725** .000 33	1.000 .000 33	.391* .024 33	-.586 .075 10	-.479 .161 10
Matched most helpful professional's INSTRUCT score	Pearson Correlation Sig. (2-tailed) N	-.134 .457 33	.291 .100 33	.391* .024 33	1.000 .000 33	.301 .398 10	.048 .896 10
Matched Least helpful professional's BLAME score	Pearson Correlation Sig. (2-tailed) N	-.179 .621 10	-.591 .072 10	-.586 .075 10	.301 .398 10	1.000 .000 13	.437 .135 13
Matched Least helpful professional's INFORM score	Pearson Correlation Sig. (2-tailed) N	.085 .816 10	-.717* .020 10	-.479 .161 10	.048 .896 10	.437 .135 13	1.000 .000 13
Matched Least helpful professional's VALIDATE score	Pearson Correlation Sig. (2-tailed) N	-.145 .690 10	-.683* .030 10	-.593 .071 10	-.034 .925 10	.738** .004 13	.431 .141 13
Matched Least helpful professionals INSTRUCT score	Pearson Correlation Sig. (2-tailed) N	.062 .865 10	.232 .518 10	.275 .442 10	-.573 .083 10	-.476 .100 13	-.144 .638 13
Is contact ongoing with the most helpful professional?	Pearson Correlation Sig. (2-tailed) N	.052 .774 33	.035 .848 33	-.166 .356 33	-.058 .749 33	.018 .953 13	-.208 .494 13
Is contact ongoing with the least helpful professional?	Pearson Correlation Sig. (2-tailed) N	.039 .838 30	-.195 .301 30	-.184 .330 30	-.103 .588 30	.332 .268 13	.461 .113 13



### Correlations

		Matched most helpful professional's BLAME score	Matched most helpful professional's INFORM score	Matched most helpful professional's VALIDATE score	Matched most helpful professional's INSTRUCT score	Matched Least helpful professional's BLAME score	Matched Least helpful professional's INFORM score
Number of contacts with most helpful professional.	Pearson Correlation	-.019	-.041	.045	.082	.204	-.239
	Sig. (2-tailed)	.919	.826	.808	.654	.503	.432
	N	32	32	32	32	13	13
Number of contacts with least helpful professional.	Pearson Correlation	-.087	-.373*	-.427*	-.314	-.193	-.048
	Sig. (2-tailed)	.652	.046	.021	.098	.527	.877
	N	29	29	29	29	13	13
Length of contact with most helpful professional in months.	Pearson Correlation	-.072	.206	.170	-.123	-.146	-.660*
	Sig. (2-tailed)	.705	.276	.369	.517	.635	.014
	N	30	30	30	30	13	13
Length of contact with least helpful professional in months.	Pearson Correlation	-.138	-.293	-.379*	-.408*	-.279	.230
	Sig. (2-tailed)	.484	.130	.047	.031	.356	.450
	N	28	28	28	28	13	13
Parent's understanding of most helpful professional role.	Pearson Correlation	-.007	.204	.131	.110	.042	-.034
	Sig. (2-tailed)	.970	.254	.468	.541	.892	.911
	N	33	33	33	33	13	13
Parent's understanding of least helpful professional role.	Pearson Correlation	-.103	.159	.353	.222	-.436	-.065
	Sig. (2-tailed)	.596	.410	.060	.248	.136	.832
	N	29	29	29	29	13	13
Parents' beliefs about parents on the blame factor.	Pearson Correlation	.157	.192	.163	.316	.180	.365
	Sig. (2-tailed)	.382	.284	.365	.073	.555	.221
	N	33	33	33	33	13	13
Parents' beliefs about parents on the inform factor: transformed.	Pearson Correlation	.135	.133	.242	-.023	-.159	-.035
	Sig. (2-tailed)	.455	.462	.175	.898	.604	.910
	N	33	33	33	33	13	13
Parents' beliefs about parents on the validate factor.	Pearson Correlation	.273	.109	.223	-.031	-.006	.034
	Sig. (2-tailed)	.125	.544	.212	.866	.986	.912
	N	33	33	33	33	13	13



### Correlations

		Matched most helpful professional's BLAME score	Matched most helpful professional's INFORM score	Matched most helpful professional's VALIDATE score	Matched most helpful professional's INSTRUCT score	Matched Least helpful professional's BLAME score	Matched Least helpful professional's INFORM score
Parents' beliefs about parents on the instruct factor: transformed.	Pearson Correlation Sig. (2-tailed) N	.179 .319 33	.031 .864 33	-.147 .415 33	.007 .968 33	.301 .318 13	.044 .886 13
Partner/spouse helpfulness on FSS.	Pearson Correlation Sig. (2-tailed) N	-.524** .002 32	-.265 .142 32	-.371* .037 32	.090 .625 32	.569* .042 13	-.125 .684 13
Informal kinship support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.239 .187 32	.038 .836 32	-.011 .951 32	.230 .206 32	.164 .592 13	-.313 .297 13
Formal kinship support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.328 .067 32	-.028 .879 32	-.183 .316 32	-.074 .687 32	.013 .968 13	-.537 .058 13
Social organisations support on FSS.	Pearson Correlation Sig. (2-tailed) N	.143 .434 32	.171 .351 32	.173 .343 32	.106 .565 32	-.233 .443 13	-.196 .521 13
Professional services support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.195 .284 32	.050 .786 32	.149 .415 32	.249 .169 32	-.067 .829 13	-.127 .679 13
Total support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.281 .120 32	.004 .983 32	-.041 .825 32	.178 .330 32	.120 .695 13	-.387 .192 13
Parent distress score on PSI.	Pearson Correlation Sig. (2-tailed) N	.210 .242 33	.003 .985 33	.075 .680 33	-.197 .272 33	.071 .817 13	.148 .630 13
Parent - child dysfunctional interaction score on PSI.	Pearson Correlation Sig. (2-tailed) N	-.001 .997 33	-.010 .954 33	.067 .711 33	-.111 .540 33	-.324 .281 13	.339 .257 13

### Correlations

		Matched most helpful professional's BLAME score	Matched most helpful professional's INFORM score	Matched most helpful professional's VALIDATE score	Matched most helpful professional's INSTRUCT score	Matched Least helpful professional's BLAME score	Matched Least helpful professional's INFORM score
Difficult child score on PSI.	Pearson Correlation	-.023	.250	.146	-.128	-.497	-.136
	Sig. (2-tailed)	.899	.161	.417	.479	.084	.657
	N	33	33	33	33	13	13
Total score on PSI.	Pearson Correlation	.087	.088	.105	-.168	-.218	.191
	Sig. (2-tailed)	.630	.625	.562	.351	.475	.532
	N	33	33	33	33	13	13
Transformed ABC irritability factor	Pearson Correlation	.013	.076	.030	-.022	-.323	.246
	Sig. (2-tailed)	.941	.674	.867	.904	.282	.418
	N	33	33	33	33	13	13
Transformed ABC lethargy factor.	Pearson Correlation	-.036	.066	-.144	-.123	-.152	.145
	Sig. (2-tailed)	.841	.716	.424	.496	.621	.637
	N	33	33	33	33	13	13
Transformed ABC stereotype factor	Pearson Correlation	-.028	.222	.196	.129	-.345	-.341
	Sig. (2-tailed)	.878	.214	.274	.476	.248	.254
	N	33	33	33	33	13	13
ABC hyperactivity factor	Pearson Correlation	.116	.060	.101	.016	-.284	.013
	Sig. (2-tailed)	.522	.739	.575	.929	.346	.965
	N	33	33	33	33	13	13
ABC inappropriate speech factor.	Pearson Correlation	.481**	.070	.128	-.215	-.335	.170
	Sig. (2-tailed)	.005	.697	.479	.229	.263	.579
	N	33	33	33	33	13	13
Total score on ABC.	Pearson Correlation	.078	.091	.059	-.007	-.254	.173
	Sig. (2-tailed)	.665	.614	.744	.968	.402	.573
	N	33	33	33	33	13	13

### Correlations

		Matched Least helpful professiona's VALIDATE score	Matched Least helpful professionals INSTRUCT score	Is contact ongoing with the most helpful professional?	Is contact ongoing with the least helpful professional?	Number of contacts with most helpful professional.	Number of contacts with least helpful professional.
Transformed HBCL score for professionals named as most helpful.	Pearson Correlation Sig. (2-tailed) N	.038 .902 13	-.476 .100 13	.037 .809 46	-.185 .248 41	-.121 .428 45	.273 .093 39
Transformed HBCL score for professionals named as least helpful.	Pearson Correlation Sig. (2-tailed) N	-.084 .785 13	-.001 .998 13	.192 .242 39	.036 .830 39	.003 .986 39	.085 .612 38
Age of the individual completing the questionnaire.	Pearson Correlation Sig. (2-tailed) N	-.187 .540 13	.151 .621 13	.148 .326 46	.098 .540 41	.205 .178 45	-.118 .474 39
Is at least one member of the family in employment?	Pearson Correlation Sig. (2-tailed) N	.025 .937 13	.192 .529 13	-.086 .568 46	-.135 .399 41	-.051 .738 45	.073 .657 39
Marital status	Pearson Correlation Sig. (2-tailed) N	.453 .120 13	-.568* .043 13	.045 .769 46	.158 .323 41	.109 .474 45	-.167 .309 39
Child's age	Pearson Correlation Sig. (2-tailed) N	.175 .568 13	.120 .695 13	.238 .112 46	.380* .014 41	.059 .701 45	-.097 .557 39
Child's gender	Pearson Correlation Sig. (2-tailed) N	.104 .735 13	-.058 .851 13	.120 .429 46	.003 .986 41	.219 .149 45	.149 .366 39
Matched most helpful professional's BLAME score	Pearson Correlation Sig. (2-tailed) N	-.145 .690 10	.062 .865 10	.052 .774 33	.039 .838 30	-.019 .919 32	-.087 .652 29

### Correlations

		Matched Least helpful professional's VALIDATE score	Matched Least helpful professionals INSTRUCT score	Is contact ongoing with the most helpful professional?	Is contact ongoing with the least helpful professional?	Number of contacts with most helpful professional.	Number of contacts with least helpful professional.
Matched most helpful professional's INFORM score	Pearson Correlation	-.683*	.232	.035	-.195	-.041	-.373*
	Sig. (2-tailed)	.030	.518	.848	.301	.826	.046
	N	10	10	33	30	32	29
Matched most helpful professional's VALIDATE score	Pearson Correlation	-.593	.275	-.166	-.184	.045	-.427*
	Sig. (2-tailed)	.071	.442	.356	.330	.808	.021
	N	10	10	33	30	32	29
Matched most helpful professional's INSTRUCT score	Pearson Correlation	-.034	-.573	-.058	-.103	.082	-.314
	Sig. (2-tailed)	.925	.083	.749	.588	.654	.098
	N	10	10	33	30	32	29
Matched Least helpful professional's BLAME score	Pearson Correlation	.738**	-.476	.018	.332	.204	-.193
	Sig. (2-tailed)	.004	.100	.953	.268	.503	.527
	N	13	13	13	13	13	13
Matched Least helpful professional's INFORM score	Pearson Correlation	.431	-.144	-.208	.461	-.239	-.048
	Sig. (2-tailed)	.141	.638	.494	.113	.432	.877
	N	13	13	13	13	13	13
Matched Least helpful professional's VALIDATE score	Pearson Correlation	1.000	.155	-.055	-.029	.204	-.113
	Sig. (2-tailed)	.	.613	.858	.925	.503	.713
	N	13	13	13	13	13	13
Matched Least helpful professionals INSTRUCT score	Pearson Correlation	.155	1.000	-.183	-.466	-.208	.316
	Sig. (2-tailed)	.613	.	.550	.109	.496	.292
	N	13	13	13	13	13	13
Is contact ongoing with the most helpful professional?	Pearson Correlation	-.055	-.183	1.000	.156	-.135	.256
	Sig. (2-tailed)	.858	.550	.	.329	.378	.115
	N	13	13	46	41	45	39
Is contact ongoing with the least helpful professional?	Pearson Correlation	-.029	-.466	.156	1.000	-.208	-.201
	Sig. (2-tailed)	.925	.109	.329	.	.192	.220
	N	13	13	41	41	41	39

### Correlations

		Matched Least helpful professiona's VALIDATE score	Matched Least helpful professionals INSTRUCT score	Is contact ongoing with the most helpful professional?	Is contact ongoing with the least helpful professional?	Number of contacts with most helpful professional.	Number of contacts with least helpful professional.
Number of contacts with most helpful professional.	Pearson Correlation Sig. (2-tailed) N	.204 .503 13	-.208 .496 13	-.135 .378 45	-.208 .192 41	1.000 .45	.044 .791 39
Number of contacts with least helpful professional.	Pearson Correlation Sig. (2-tailed) N	-.113 .713 13	.316 .292 13	.256 .115 39	-.201 .220 39	.044 .791 39	1.000 .39
Length of contact with most helpful professional in months.	Pearson Correlation Sig. (2-tailed) N	-.438 .134 13	-.228 .454 13	-.214 .167 43	.133 .419 39	.470** .001 43	-.039 .817 37
Length of contact with least helpful professional in months.	Pearson Correlation Sig. (2-tailed) N	-.182 .553 13	.196 .521 13	.051 .765 37	-.063 .710 37	-.231 .169 37	.555** .000 37
Parent's understanding of most helpful professional role.	Pearson Correlation Sig. (2-tailed) N	-.403 .172 13	-.567* .043 13	-.020 .896 46	.019 .906 41	-.194 .202 45	-.161 .328 39
Parent's understanding of least helpful professional role.	Pearson Correlation Sig. (2-tailed) N	-.242 .426 13	.295 .328 13	.147 .366 40	.352* .026 40	-.327* .039 40	-.187 .255 39
Parents' beliefs about parents on the blame factor.	Pearson Correlation Sig. (2-tailed) N	.099 .749 13	-.102 .740 13	.214 .154 46	-.043 .788 41	-.031 .839 45	-.073 .658 39
Parents' beliefs about parents on the inform factor: transformed.	Pearson Correlation Sig. (2-tailed) N	-.096 .756 13	.162 .598 13	.080 .596 46	-.122 .448 41	.128 .401 45	-.062 .709 39
Parents' beliefs about parents on the validate factor.	Pearson Correlation Sig. (2-tailed) N	-.147 .631 13	-.154 .615 13	.073 .628 46	-.035 .830 41	.024 .873 45	.224 .170 39

### Correlations

		Matched Least helpful professiona's VALIDATE score	Matched Least helpful professionals INSTRUCT score	Is contact ongoing with the most helpful professional?	Is contact ongoing with the least helpful professional?	Number of contacts with most helpful professional.	Number of contacts with least helpful professional.
Parents' beliefs about parents on the instruct factor: transformed.	Pearson Correlation Sig. (2-tailed) N	-.003 .993 13	-.449 .124 13	-.047 .757 46	.040 .802 41	.314* .036 45	.170 .302 39
Partner/spouse helpfulness on FSS.	Pearson Correlation Sig. (2-tailed) N	.451 .122 13	-.292 .332 13	-.015 .924 45	.010 .949 41	.189 .219 44	-.058 .727 39
Informal kinship support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.155 .614 13	-.339 .258 13	.224 .139 45	.094 .558 41	.243 .112 44	-.115 .487 39
Formal kinship support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.153 .618 13	.040 .897 13	-.047 .761 45	.003 .987 41	.039 .804 44	-.113 .492 39
Social organisations support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.545 .054 13	-.278 .359 13	.151 .324 45	.306 .052 41	.016 .920 44	.033 .842 39
Professional services support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.377 .204 13	-.272 .368 13	-.259 .086 45	.025 .877 41	-.149 .335 44	-.170 .301 39
Total support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.276 .361 13	-.379 .201 13	.041 .790 45	.137 .392 41	.108 .485 44	-.115 .484 39
Parent distress score on PSI.	Pearson Correlation Sig. (2-tailed) N	-.136 .658 13	-.343 .251 13	-.155 .304 46	-.374* .016 41	.018 .907 45	-.077 .642 39
Parent - child dysfunctional interaction score on PSI.	Pearson Correlation Sig. (2-tailed) N	-.334 .264 13	-.146 .635 13	-.067 .659 46	-.043 .788 41	-.092 .546 45	-.192 .243 39

### Correlations

		Matched Least helpful professiona's VALIDATE score	Matched Least helpful professionals INSTRUCT score	Is contact ongoing with the most helpful professional?	Is contact ongoing with the least helpful professional?	Number of contacts with most helpful professional.	Number of contacts with least helpful professional.
Difficult child score on PSI.	Pearson Correlation	-.430	.151	-.117	-.162	-.276	-.292
	Sig. (2-tailed)	.142	.622	.437	.312	.066	.071
	N	13	13	46	41	45	39
Total score on PSI.	Pearson Correlation	-.312	-.176	-.128	-.237	-.135	-.209
	Sig. (2-tailed)	.300	.564	.396	.136	.376	.202
	N	13	13	46	41	45	39
Transformed ABC irritability factor	Pearson Correlation	-.122	.267	-.296*	-.100	-.139	-.252
	Sig. (2-tailed)	.692	.378	.045	.532	.362	.121
	N	13	13	46	41	45	39
Transformed ABC lethargy factor.	Pearson Correlation	.014	.036	.075	-.116	-.276	.014
	Sig. (2-tailed)	.963	.908	.620	.470	.067	.932
	N	13	13	46	41	45	39
Transformed ABC stereotype factor	Pearson Correlation	-.242	.000	-.261	.022	.071	-.332*
	Sig. (2-tailed)	.426	.999	.080	.889	.644	.039
	N	13	13	46	41	45	39
ABC hyperactivity factor	Pearson Correlation	-.201	-.016	-.116	-.047	-.023	-.196
	Sig. (2-tailed)	.511	.959	.445	.771	.881	.231
	N	13	13	46	41	45	39
ABC inappropriate speech factor.	Pearson Correlation	-.131	.137	-.166	-.069	.043	-.235
	Sig. (2-tailed)	.669	.655	.269	.667	.779	.150
	N	13	13	46	41	45	39
Total score on ABC.	Pearson Correlation	-.162	-.055	-.164	-.049	-.068	-.283
	Sig. (2-tailed)	.596	.859	.276	.760	.658	.081
	N	13	13	46	41	45	39

### Correlations

		Length of contact with most helpful professional in months.	Length of contact with least helpful professional in months.	Parent's understandi ng of most helpful professional role.	Parent's understandi ng of least helpful professional role.	Parents' beliefs about parents on the blame factor.	Parents' beliefs about parents on the inform factor: transformed.	Parents' beliefs about parents on the validate factor.
Transformed HBCL score for professionals named as most helpful.	Pearson Correlation Sig. (2-tailed) N	-.028 .859 43	-.069 .685 37	.240 .108 46	-.323* .042 40	-.140 .354 46	.211 .159 46	.211 .159 46
Transformed HBCL score for professionals named as least helpful.	Pearson Correlation Sig. (2-tailed) N	-.242 .149 37	-.044 .799 36	.171 .297 39	.198 .227 39	-.257 .114 39	-.039 .813 39	-.339* .035 39
Age of the individual completing the questionnaire.	Pearson Correlation Sig. (2-tailed) N	.094 .550 43	-.062 .715 37	-.092 .543 46	.160 .324 40	.221 .139 46	.126 .404 46	.100 .508 46
Is at least one member of the family in employment?	Pearson Correlation Sig. (2-tailed) N	-.212 .172 43	-.041 .811 37	-.193 .199 46	.169 .297 40	.083 .584 46	.069 .649 46	.222 .138 46
Marital status	Pearson Correlation Sig. (2-tailed) N	.057 .714 43	-.066 .698 37	.157 .298 46	-.201 .214 40	.105 .488 46	.022 .883 46	-.099 .512 46
Child's age	Pearson Correlation Sig. (2-tailed) N	-.067 .667 43	-.031 .856 37	-.232 .120 46	.123 .451 40	.171 .256 46	-.018 .904 46	.217 .148 46
Child's gender	Pearson Correlation Sig. (2-tailed) N	-.006 .970 43	-.004 .982 37	-.166 .271 46	-.089 .583 40	.277 .063 46	.174 .247 46	.131 .385 46
Matched most helpful professional's BLAME score	Pearson Correlation Sig. (2-tailed) N	-.072 .705 30	-.138 .484 28	-.007 .970 33	-.103 .596 29	.157 .382 33	.135 .455 33	.273 .125 33



### Correlations

		Length of contact with most helpful professional in months.	Length of contact with least helpful professional in months.	Parent's understandi ng of most helpful professional role.	Parent's understandi ng of least helpful professional role.	Parents' beliefs about parents on the blame factor.	Parents' beliefs about parents on the inform factor: transformed.	Parents' beliefs about parents on the validate factor.
Matched most helpful professional's INFORM score	Pearson Correlation Sig. (2-tailed) N	.206 .276 30	-.293 .130 28	.204 .254 33	.159 .410 29	.192 .284 33	.133 .462 33	.109 .544 33
Matched most helpful professional's VALIDATE score	Pearson Correlation Sig. (2-tailed) N	.170 .369 30	-.379* .047 28	.131 .468 33	.353 .060 29	.163 .365 33	.242 .175 33	.223 .212 33
Matched most helpful professional's INSTRUCT score	Pearson Correlation Sig. (2-tailed) N	-.123 .517 30	-.408* .031 28	.110 .541 33	.222 .248 29	.316 .073 33	-.023 .898 33	-.031 .866 33
Matched Least helpful professional's BLAME score	Pearson Correlation Sig. (2-tailed) N	-.146 .635 13	-.279 .356 13	.042 .892 13	-.436 .136 13	.180 .555 13	-.159 .604 13	-.006 .986 13
Matched Least helpful professional's INFORM score	Pearson Correlation Sig. (2-tailed) N	-.660* .014 13	.230 .450 13	-.034 .911 13	-.065 .832 13	.365 .221 13	-.035 .910 13	.034 .912 13
Matched Least helpful professiona's VALIDATE score	Pearson Correlation Sig. (2-tailed) N	-.438 .134 13	-.182 .553 13	-.403 .172 13	-.242 .426 13	.099 .749 13	-.096 .756 13	-.147 .631 13
Matched Least helpful professionals INSTRUCT score	Pearson Correlation Sig. (2-tailed) N	-.228 .454 13	.196 .521 13	-.567* .043 13	.295 .328 13	-.102 .740 13	.162 .598 13	-.154 .615 13
Is contact ongoing with the most helpful professional?	Pearson Correlation Sig. (2-tailed) N	-.214 .167 43	.051 .765 37	-.020 .896 46	.147 .366 40	.214 .154 46	.080 .596 46	.073 .628 46
Is contact ongoing with the least helpful professional?	Pearson Correlation Sig. (2-tailed) N	.133 .419 39	-.063 .710 37	.019 .906 41	.352* .026 40	-.043 .788 41	-.122 .448 41	-.035 .830 41

### Correlations

		Length of contact with most helpful professional in months.	Length of contact with least helpful professional in months.	Parent's understandi ng of most helpful professional role.	Parent's understandi ng of least helpful professional role.	Parents' beliefs about parents on the blame factor.	Parents' beliefs about parents on the inform factor: transformed.	Parents' beliefs about parents on the validate factor.
Number of contacts with most helpful professional.	Pearson Correlation Sig. (2-tailed) N	.470** .001 43	-.231 .169 37	-.194 .202 45	-.327* .039 40	-.031 .839 45	.128 .401 45	.024 .873 45
Number of contacts with least helpful professional.	Pearson Correlation Sig. (2-tailed) N	-.039 .817 37	.555** .000 37	-.161 .328 39	-.187 .255 39	-.073 .658 39	-.062 .709 39	.224 .170 39
Length of contact with most helpful professional in months.	Pearson Correlation Sig. (2-tailed) N	1.000 .43	-.072 .674 36	-.116 .459 43	-.084 .615 38	-.127 .417 43	.196 .207 43	-.036 .819 43
Length of contact with least helpful professional in months.	Pearson Correlation Sig. (2-tailed) N	-.072 .674 36	1.000 .821 37	-.038 .821 37	-.026 .879 37	-.060 .724 37	-.175 .301 37	.075 .660 37
Parent's understanding of most helpful professional role.	Pearson Correlation Sig. (2-tailed) N	-.116 .459 43	-.038 .821 37	1.000 .881 46	-.025 .881 40	.016 .913 46	-.154 .308 46	-.082 .590 46
Parent's understanding of least helpful professional role.	Pearson Correlation Sig. (2-tailed) N	-.084 .615 38	-.026 .879 37	-.025 .881 40	1.000 .961 40	.008 .961 40	-.229 .156 40	-.169 .296 40
Parents' beliefs about parents on the blame factor.	Pearson Correlation Sig. (2-tailed) N	-.127 .417 43	-.060 .724 37	.016 .913 46	.008 .961 40	1.000 .961 46	.285 .055 46	.307* .038 46
Parents' beliefs about parents on the inform factor: transformed.	Pearson Correlation Sig. (2-tailed) N	.196 .207 43	-.175 .301 37	-.154 .308 46	-.229 .156 40	.285 .055 46	1.000 .961 46	.364* .013 46
Parents' beliefs about parents on the validate factor.	Pearson Correlation Sig. (2-tailed) N	-.036 .819 43	.075 .660 37	-.082 .590 46	-.169 .296 40	.307* .038 46	.364* .013 46	1.000 .961 46

### Correlations

		Length of contact with most helpful professional in months.	Length of contact with least helpful professional in months.	Parent's understandi ng of most helpful professional role.	Parent's understandi ng of least helpful professional role.	Parents' beliefs about parents on the blame factor.	Parents' beliefs about parents on the inform factor: transformed.	Parents' beliefs about parents on the validate factor.
Parents' beliefs about parents on the instruct factor: transformed.	Pearson Correlation Sig. (2-tailed) N	.178 .254 43	-.133 .432 37	-.142 .347 46	-.382* .015 40	-.061 .685 46	.164 .276 46	.267 .073 46
Partner/spouse helpfulness on FSS.	Pearson Correlation Sig. (2-tailed) N	.257 .101 42	.051 .763 37	.109 .476 45	-.199 .218 40	.057 .709 45	-.172 .259 45	-.233 .123 45
Informal kinship support on FSS.	Pearson Correlation Sig. (2-tailed) N	.214 .173 42	-.042 .807 37	-.086 .575 45	.091 .575 40	.044 .775 45	-.297* .047 45	-.302* .044 45
Formal kinship support on FSS.	Pearson Correlation Sig. (2-tailed) N	.229 .145 42	.029 .863 37	-.029 .852 45	-.060 .715 40	-.094 .537 45	-.217 .151 45	-.119 .436 45
Social organisations support on FSS.	Pearson Correlation Sig. (2-tailed) N	.363* .018 42	.194 .249 37	-.108 .480 45	.147 .366 40	.005 .973 45	-.163 .285 45	-.157 .302 45
Professional services support on FSS.	Pearson Correlation Sig. (2-tailed) N	.157 .321 42	.234 .163 37	.147 .335 45	.124 .447 40	.129 .399 45	-.232 .125 45	-.245 .105 45
Total support on FSS.	Pearson Correlation Sig. (2-tailed) N	.342* .027 42	.129 .446 37	.000 1.000 45	.047 .775 40	.045 .768 45	-.302* .044 45	-.301* .044 45
Parent distress score on PSI.	Pearson Correlation Sig. (2-tailed) N	.034 .828 43	-.037 .826 37	.272 .068 46	-.243 .131 40	.127 .401 46	.221 .140 46	.086 .571 46
Parent - child dysfunctional interaction score on PSI.	Pearson Correlation Sig. (2-tailed) N	-.037 .812 43	-.013 .938 37	.142 .348 46	.061 .708 40	.037 .805 46	.110 .468 46	-.011 .943 46

### Correlations

		Length of contact with most helpful professional in months.	Length of contact with least helpful professional in months.	Parent's understandi ng of most helpful professional role.	Parent's understandi ng of least helpful professional role.	Parents' beliefs about parents on the blame factor.	Parents' beliefs about parents on the inform factor: transformed.	Parents' beliefs about parents on the validate factor.
Difficult child score on PSI.	Pearson Correlation	-.177	.120	.286	.291	.024	-.118	-.083
	Sig. (2-tailed)	.255	.479	.054	.069	.876	.433	.583
	N	43	37	46	40	46	46	46
Total score on PSI.	Pearson Correlation	-.073	.035	.280	.027	.086	.077	.000
	Sig. (2-tailed)	.644	.839	.059	.871	.568	.611	.999
	N	43	37	46	40	46	46	46
Transformed ABC irritability factor	Pearson Correlation	-.245	.047	.243	.084	-.126	-.010	-.045
	Sig. (2-tailed)	.113	.784	.104	.605	.404	.949	.764
	N	43	37	46	40	46	46	46
Transformed ABC lethargy factor.	Pearson Correlation	-.215	.124	.326*	.050	-.103	-.075	-.264
	Sig. (2-tailed)	.165	.463	.027	.757	.497	.619	.076
	N	43	37	46	40	46	46	46
Transformed ABC stereotype factor	Pearson Correlation	.187	-.142	.178	.228	-.284	-.162	-.282
	Sig. (2-tailed)	.230	.400	.238	.156	.056	.281	.058
	N	43	37	46	40	46	46	46
ABC hyperactivity factor	Pearson Correlation	-.079	-.063	.330*	.211	-.146	-.030	-.138
	Sig. (2-tailed)	.616	.712	.025	.191	.334	.841	.361
	N	43	37	46	40	46	46	46
ABC inappropriate speech factor.	Pearson Correlation	-.145	-.071	.238	-.045	-.123	-.103	.046
	Sig. (2-tailed)	.352	.674	.111	.785	.415	.495	.759
	N	43	37	46	40	46	46	46
Total score on ABC.	Pearson Correlation	-.162	.004	.371*	.184	-.123	-.087	-.166
	Sig. (2-tailed)	.298	.980	.011	.257	.414	.564	.271
	N	43	37	46	40	46	46	46

### Correlations

		Parents' beliefs about parents on the instruct factor: transformed.	Partner/spouse helpfulness on FSS.	Informal kinship support on FSS.	Formal kinship support on FSS.	Social organisations support on FSS.	Professional services support on FSS.	Total support on FSS.
Transformed HBCL score for professionals named as most helpful.	Pearson Correlation Sig. (2-tailed) N	.085 .573 46	-.026 .865 45	-.512** .000 45	-.201 .186 45	-.322* .031 45	-.258 .087 45	-.385** .009 45
Transformed HBCL score for professionals named as least helpful.	Pearson Correlation Sig. (2-tailed) N	.108 .515 39	-.170 .302 39	.011 .947 39	-.123 .454 39	.034 .836 39	-.125 .447 39	-.091 .582 39
Age of the individual completing the questionnaire.	Pearson Correlation Sig. (2-tailed) N	.129 .393 46	-.301* .045 45	.091 .552 45	-.342* .021 45	.040 .794 45	-.197 .194 45	-.162 .286 45
Is at least one member of the family in employment?	Pearson Correlation Sig. (2-tailed) N	.174 .248 46	-.517** .000 45	-.319* .033 45	-.324* .030 45	-.245 .104 45	-.188 .217 45	-.440** .002 45
Marital status	Pearson Correlation Sig. (2-tailed) N	-.086 .570 46	.611** .000 45	.161 .290 45	.030 .845 45	.042 .785 45	.078 .610 45	.261 .083 45
Child's age	Pearson Correlation Sig. (2-tailed) N	.180 .232 46	-.141 .356 45	.131 .390 45	-.273 .070 45	.112 .466 45	-.148 .333 45	-.056 .716 45
Child's gender	Pearson Correlation Sig. (2-tailed) N	.233 .119 46	-.123 .421 45	.132 .389 45	.022 .886 45	-.101 .508 45	-.234 .122 45	-.076 .619 45
Matched most helpful professional's BLAME score	Pearson Correlation Sig. (2-tailed) N	.179 .319 33	-.524** .002 32	-.239 .187 32	-.328 .067 32	.143 .434 32	-.195 .284 32	-.281 .120 32

### Correlations

		Parents' beliefs about parents on the instruct factor: transformed.	Partner/spouse helpfulness on FSS.	Informal kinship support on FSS.	Formal kinship support on FSS.	Social organisations support on FSS.	Professional services support on FSS.	Total support on FSS.
Matched most helpful professional's INFORM score	Pearson Correlation Sig. (2-tailed) N	.031 .864 33	-.265 .142 32	.038 .836 32	-.028 .879 32	.171 .351 32	.050 .786 32	.004 .983 32
Matched most helpful professional's VALIDATE score	Pearson Correlation Sig. (2-tailed) N	-.147 .415 33	-.371* .037 32	-.011 .951 32	-.183 .316 32	.173 .343 32	.149 .415 32	-.041 .825 32
Matched most helpful professional's INSTRUCT score	Pearson Correlation Sig. (2-tailed) N	.007 .968 33	.090 .625 32	.230 .206 32	-.074 .687 32	.106 .565 32	.249 .169 32	.178 .330 32
Matched Least helpful professional's BLAME score	Pearson Correlation Sig. (2-tailed) N	.301 .318 13	.569* .042 13	.164 .592 13	.013 .968 13	-.233 .443 13	-.067 .829 13	.120 .695 13
Matched Least helpful professional's INFORM score	Pearson Correlation Sig. (2-tailed) N	.044 .886 13	-.125 .684 13	-.313 .297 13	-.537 .058 13	-.196 .521 13	-.127 .679 13	-.387 .192 13
Matched Least helpful professional's VALIDATE score	Pearson Correlation Sig. (2-tailed) N	-.003 .993 13	.451 .122 13	-.155 .614 13	-.153 .618 13	-.545 .054 13	-.377 .204 13	-.276 .361 13
Matched Least helpful professionals INSTRUCT score	Pearson Correlation Sig. (2-tailed) N	-.449 .124 13	-.292 .332 13	-.339 .258 13	.040 .897 13	-.278 .359 13	-.272 .368 13	-.379 .201 13
Is contact ongoing with the most helpful professional?	Pearson Correlation Sig. (2-tailed) N	-.047 .757 46	-.015 .924 45	.224 .139 45	-.047 .761 45	.151 .324 45	-.259 .086 45	.041 .790 45
Is contact ongoing with the least helpful professional?	Pearson Correlation Sig. (2-tailed) N	.040 .802 41	.010 .949 41	.094 .558 41	.003 .987 41	.306 .052 41	.025 .877 41	.137 .392 41

### Correlations

		Parents' beliefs about parents on the instruct factor: transformed.	Partner/spouse helpfulness on FSS.	Informal kinship support on FSS.	Formal kinship support on FSS.	Social organisations support on FSS.	Professional services support on FSS.	Total support on FSS.
Number of contacts with most helpful professional.	Pearson Correlation	.314*	.189	.243	.039	.016	-.149	.108
	Sig. (2-tailed)	.036	.219	.112	.804	.920	.335	.485
	N	45	44	44	44	44	44	44
Number of contacts with least helpful professional.	Pearson Correlation	.170	-.058	-.115	-.113	.033	-.170	-.115
	Sig. (2-tailed)	.302	.727	.487	.492	.842	.301	.484
	N	39	39	39	39	39	39	39
Length of contact with most helpful professional in months.	Pearson Correlation	.178	.257	.214	.229	.363*	.157	.342*
	Sig. (2-tailed)	.254	.101	.173	.145	.018	.321	.027
	N	43	42	42	42	42	42	42
Length of contact with least helpful professional in months.	Pearson Correlation	-.133	.051	-.042	.029	.194	.234	.129
	Sig. (2-tailed)	.432	.763	.807	.863	.249	.163	.446
	N	37	37	37	37	37	37	37
Parent's understanding of most helpful professional role.	Pearson Correlation	-.142	.109	-.086	-.029	-.108	.147	.000
	Sig. (2-tailed)	.347	.476	.575	.852	.480	.335	1.000
	N	46	45	45	45	45	45	45
Parent's understanding of least helpful professional role.	Pearson Correlation	-.382*	-.199	.091	-.060	.147	.124	.047
	Sig. (2-tailed)	.015	.218	.575	.715	.366	.447	.775
	N	40	40	40	40	40	40	40
Parents' beliefs about parents on the blame factor.	Pearson Correlation	-.061	.057	.044	-.094	.005	.129	.045
	Sig. (2-tailed)	.685	.709	.775	.537	.973	.399	.768
	N	46	45	45	45	45	45	45
Parents' beliefs about parents on the inform factor: transformed.	Pearson Correlation	.164	-.172	-.297*	-.217	-.163	-.232	-.302*
	Sig. (2-tailed)	.276	.259	.047	.151	.285	.125	.044
	N	46	45	45	45	45	45	45
Parents' beliefs about parents on the validate factor.	Pearson Correlation	.267	-.233	-.302*	-.119	-.157	-.245	-.301*
	Sig. (2-tailed)	.073	.123	.044	.436	.302	.105	.044
	N	46	45	45	45	45	45	45



### Correlations

		Parents' beliefs about parents on the instruct factor: transformed.	Partner/spouse helpfulness on FSS.	Informal kinship support on FSS.	Formal kinship support on FSS.	Social organisations support on FSS.	Professional services support on FSS.	Total support on FSS.
Parents' beliefs about parents on the instruct factor: transformed.	Pearson Correlation	1.000	-.180	-.198	-.046	-.122	-.301*	-.240
	Sig. (2-tailed)	.	.236	.192	.766	.425	.044	.112
	N	46	45	45	45	45	45	45
Partner/spouse helpfulness on FSS.	Pearson Correlation	-.180	1.000	.425**	.474**	.258	.258	.661**
	Sig. (2-tailed)	.236	.	.004	.001	.088	.088	.000
	N	45	45	45	45	45	45	45
Informal kinship support on FSS.	Pearson Correlation	-.198	.425**	1.000	.415**	.609**	.321*	.807**
	Sig. (2-tailed)	.192	.004	.	.005	.000	.031	.000
	N	45	45	45	45	45	45	45
Formal kinship support on FSS.	Pearson Correlation	-.046	.474**	.415**	1.000	.318*	.383**	.675**
	Sig. (2-tailed)	.766	.001	.005	.	.033	.009	.000
	N	45	45	45	45	45	45	45
Social organisations support on FSS.	Pearson Correlation	-.122	.258	.609**	.318*	1.000	.489**	.772**
	Sig. (2-tailed)	.425	.088	.000	.033	.	.001	.000
	N	45	45	45	45	45	45	45
Professional services support on FSS.	Pearson Correlation	-.301*	.258	.321*	.383**	.489**	1.000	.665**
	Sig. (2-tailed)	.044	.088	.031	.009	.001	.	.000
	N	45	45	45	45	45	45	45
Total support on FSS.	Pearson Correlation	-.240	.661**	.807**	.675**	.772**	.665**	1.000
	Sig. (2-tailed)	.112	.000	.000	.000	.000	.000	.
	N	45	45	45	45	45	45	45
Parent distress score on PSI.	Pearson Correlation	.050	-.045	-.461**	-.371*	-.308*	.010	-.336*
	Sig. (2-tailed)	.739	.768	.001	.012	.039	.948	.024
	N	46	45	45	45	45	45	45
Parent - child dysfunctional interaction score on PSI.	Pearson Correlation	-.226	.018	-.391**	-.318*	-.130	.078	-.212
	Sig. (2-tailed)	.131	.904	.008	.033	.395	.611	.162
	N	46	45	45	45	45	45	45



### Correlations

		Parents' beliefs about parents on the instruct factor: transformed.	Partner/spouse helpfulness on FSS.	Informal kinship support on FSS.	Formal kinship support on FSS.	Social organisations support on FSS.	Professional services support on FSS.	Total support on FSS.
Difficult child score on PSI.	Pearson Correlation	-.311*	-.110	-.302*	-.160	-.137	.245	-.144
	Sig. (2-tailed)	.035	.473	.044	.295	.369	.105	.346
	N	46	45	45	45	45	45	45
Total score on PSI.	Pearson Correlation	-.175	-.054	-.450**	-.335*	-.227	.136	-.270
	Sig. (2-tailed)	.246	.723	.002	.024	.133	.372	.073
	N	46	45	45	45	45	45	45
Transformed ABC irritability factor	Pearson Correlation	-.173	-.141	-.315*	-.333*	-.277	-.066	-.316*
	Sig. (2-tailed)	.251	.354	.035	.026	.066	.669	.035
	N	46	45	45	45	45	45	45
Transformed ABC lethargy factor.	Pearson Correlation	-.149	.007	-.347*	-.329*	-.256	-.110	-.290
	Sig. (2-tailed)	.321	.964	.019	.027	.090	.474	.054
	N	46	45	45	45	45	45	45
Transformed ABC stereotype factor	Pearson Correlation	-.176	.135	.079	.123	.200	.259	.217
	Sig. (2-tailed)	.242	.376	.604	.423	.187	.086	.152
	N	46	45	45	45	45	45	45
ABC hyperactivity factor	Pearson Correlation	-.163	-.255	-.276	-.463**	-.220	-.065	-.344*
	Sig. (2-tailed)	.278	.091	.066	.001	.147	.669	.021
	N	46	45	45	45	45	45	45
ABC inappropriate speech factor.	Pearson Correlation	-.150	-.290	-.178	-.293	-.121	-.062	-.254
	Sig. (2-tailed)	.318	.053	.241	.051	.427	.687	.093
	N	46	45	45	45	45	45	45
Total score on ABC.	Pearson Correlation	-.223	-.134	-.250	-.416**	-.199	.000	-.269
	Sig. (2-tailed)	.137	.379	.098	.004	.190	.998	.074
	N	46	45	45	45	45	45	45

### Correlations

		Parent distress score on PSI.	Parent - child dysfunctional interaction score on PSI.	Difficult child score on PSI.	Total score on PSI.	Transformed ABC irritability factor	Transformed ABC lethargy factor.	Transformed ABC stereotype factor
Transformed HBCL score for professionals named as most helpful.	Pearson Correlation Sig. (2-tailed) N	.410** .005 46	.329* .025 46	.202 .178 46	.362* .013 46	.138 .360 46	.493** .000 46	.110 .466 46
Transformed HBCL score for professionals named as least helpful.	Pearson Correlation Sig. (2-tailed) N	-.106 .519 39	-.064 .698 39	-.181 .269 39	-.148 .367 39	-.045 .786 39	.160 .330 39	.107 .516 39
Age of the individual completing the questionnaire.	Pearson Correlation Sig. (2-tailed) N	.062 .682 46	-.048 .749 46	-.039 .796 46	.003 .982 46	.093 .541 46	-.010 .949 46	.074 .626 46
Is at least one member of the family in employment?	Pearson Correlation Sig. (2-tailed) N	.114 .452 46	.192 .201 46	.207 .167 46	.178 .236 46	.211 .159 46	.263 .078 46	.122 .421 46
Marital status	Pearson Correlation Sig. (2-tailed) N	.070 .644 46	.086 .571 46	-.126 .404 46	.032 .834 46	-.036 .812 46	-.002 .991 46	.005 .974 46
Child's age	Pearson Correlation Sig. (2-tailed) N	-.169 .261 46	-.111 .464 46	-.162 .281 46	-.170 .258 46	-.107 .481 46	-.164 .275 46	-.203 .176 46
Child's gender	Pearson Correlation Sig. (2-tailed) N	-.134 .373 46	-.376** .010 46	-.442** .002 46	-.345* .019 46	-.535** .000 46	-.522** .000 46	-.638** .000 46
Matched most helpful professional's BLAME score	Pearson Correlation Sig. (2-tailed) N	.210 .242 33	-.001 .997 33	-.023 .899 33	.087 .630 33	.013 .941 33	-.036 .841 33	-.028 .878 33

### Correlations

		Parent distress score on PSI.	Parent - child dysfunctional interaction score on PSI.	Difficult child score on PSI.	Total score on PSI.	Transformed ABC irritability factor	Transformed ABC lethargy factor.	Transformed ABC stereotype factor
Matched most helpful professional's INFORM score	Pearson Correlation Sig. (2-tailed) N	.003 .985 33	-.010 .954 33	.250 .161 33	.088 .625 33	.076 .674 33	.066 .716 33	.222 .214 33
Matched most helpful professional's VALIDATE score	Pearson Correlation Sig. (2-tailed) N	.075 .680 33	.067 .711 33	.146 .417 33	.105 .562 33	.030 .867 33	-.144 .424 33	.196 .274 33
Matched most helpful professional's INSTRUCT score	Pearson Correlation Sig. (2-tailed) N	-.197 .272 33	-.111 .540 33	-.128 .479 33	-.168 .351 33	-.022 .904 33	-.123 .496 33	.129 .476 33
Matched Least helpful professional's BLAME score	Pearson Correlation Sig. (2-tailed) N	.071 .817 13	-.324 .281 13	-.497 .084 13	-.218 .475 13	-.323 .282 13	-.152 .621 13	-.345 .248 13
Matched Least helpful professional's INFORM score	Pearson Correlation Sig. (2-tailed) N	.148 .630 13	.339 .257 13	-.136 .657 13	.191 .532 13	.246 .418 13	.145 .637 13	-.341 .254 13
Matched Least helpful professiona's VALIDATE score	Pearson Correlation Sig. (2-tailed) N	-.136 .658 13	-.334 .264 13	-.430 .142 13	-.312 .300 13	-.122 .692 13	.014 .963 13	-.242 .426 13
Matched Least helpful professionals INSTRUCT score	Pearson Correlation Sig. (2-tailed) N	-.343 .251 13	-.146 .635 13	.151 .622 13	-.176 .564 13	.267 .378 13	.036 .908 13	.000 .999 13
Is contact ongoing with the most helpful professional?	Pearson Correlation Sig. (2-tailed) N	-.155 .304 46	-.067 .659 46	-.117 .437 46	-.128 .396 46	-.296* .045 46	.075 .620 46	-.261 .080 46
Is contact ongoing with the least helpful professional?	Pearson Correlation Sig. (2-tailed) N	-.374* .016 41	-.043 .788 41	-.162 .312 41	-.237 .136 41	-.100 .532 41	-.116 .470 41	.022 .889 41

### Correlations

		Parent distress score on PSI.	Parent - child dysfunctional interaction score on PSI.	Difficult child score on PSI.	Total score on PSI.	Transformed ABC irritability factor	Transformed ABC lethargy factor.	Transformed ABC stereotype factor
Number of contacts with most helpful professional.	Pearson Correlation Sig. (2-tailed) N	.018 .907 45	-.092 .546 45	-.276 .066 45	-.135 .376 45	-.139 .362 45	-.276 .067 45	.071 .644 45
Number of contacts with least helpful professional.	Pearson Correlation Sig. (2-tailed) N	-.077 .642 39	-.192 .243 39	-.292 .071 39	-.209 .202 39	-.252 .121 39	.014 .932 39	-.332* .039 39
Length of contact with most helpful professional in months.	Pearson Correlation Sig. (2-tailed) N	.034 .828 43	-.037 .812 43	-.177 .255 43	-.073 .644 43	-.245 .113 43	-.215 .165 43	.187 .230 43
Length of contact with least helpful professional in months.	Pearson Correlation Sig. (2-tailed) N	-.037 .826 37	-.013 .938 37	.120 .479 37	.035 .839 37	.047 .784 37	.124 .463 37	-.142 .400 37
Parent's understanding of most helpful professional role.	Pearson Correlation Sig. (2-tailed) N	.272 .068 46	.142 .348 46	.286 .054 46	.280 .059 46	.243 .104 46	.326* .027 46	.178 .238 46
Parent's understanding of least helpful professional role.	Pearson Correlation Sig. (2-tailed) N	-.243 .131 40	.061 .708 40	.291 .069 40	.027 .871 40	.084 .605 40	.050 .757 40	.228 .156 40
Parents' beliefs about parents on the blame factor.	Pearson Correlation Sig. (2-tailed) N	.127 .401 46	.037 .805 46	.024 .876 46	.086 .568 46	-.126 .404 46	-.103 .497 46	-.284 .056 46
Parents' beliefs about parents on the inform factor: transformed.	Pearson Correlation Sig. (2-tailed) N	.221 .140 46	.110 .468 46	-.118 .433 46	.077 .611 46	-.010 .949 46	-.075 .619 46	-.162 .281 46
Parents' beliefs about parents on the validate factor.	Pearson Correlation Sig. (2-tailed) N	.086 .571 46	-.011 .943 46	-.083 .583 46	.000 .999 46	-.045 .764 46	-.264 .076 46	-.282 .058 46

### Correlations

		Parent distress score on PSI.	Parent - child dysfunctional interaction score on PSI.	Difficult child score on PSI.	Total score on PSI.	Transformed ABC irritability factor	Transformed ABC lethargy factor.	Transformed ABC stereotype factor
Parents' beliefs about parents on the instruct factor: transformed.	Pearson Correlation Sig. (2-tailed) N	.050 .739 46	-.226 .131 46	-.311* .035 46	-.175 .246 46	-.173 .251 46	-.149 .321 46	-.176 .242 46
Partner/spouse helpfulness on FSS.	Pearson Correlation Sig. (2-tailed) N	-.045 .768 45	.018 .904 45	-.110 .473 45	-.054 .723 45	-.141 .354 45	.007 .964 45	.135 .376 45
Informal kinship support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.461** .001 45	-.391** .008 45	-.302* .044 45	-.450** .002 45	-.315* .035 45	-.347* .019 45	.079 .604 45
Formal kinship support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.371* .012 45	-.318* .033 45	-.160 .295 45	-.335* .024 45	-.333* .026 45	-.329* .027 45	.123 .423 45
Social organisations support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.308* .039 45	-.130 .395 45	-.137 .369 45	-.227 .133 45	-.277 .066 45	-.256 .090 45	.200 .187 45
Professional services support on FSS.	Pearson Correlation Sig. (2-tailed) N	.010 .948 45	.078 .611 45	.245 .105 45	.136 .372 45	-.066 .669 45	-.110 .474 45	.259 .086 45
Total support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.336* .024 45	-.212 .162 45	-.144 .346 45	-.270 .073 45	-.316* .035 45	-.290 .054 45	.217 .152 45
Parent distress score on PSI.	Pearson Correlation Sig. (2-tailed) N	1.000 .000 46	.606** .000 46	.561** .000 46	.863** .000 46	.276 .063 46	.316* .033 46	.071 .638 46
Parent - child dysfunctional interaction score on PSI.	Pearson Correlation Sig. (2-tailed) N	.606** .000 46	1.000 .000 46	.702** .000 46	.865** .000 46	.502** .000 46	.524** .000 46	.310* .036 46

### Correlations

		Parent distress score on PSI.	Parent - child dysfunctional interaction score on PSI.	Difficult child score on PSI.	Total score on PSI.	Transformed ABC irritability factor	Transformed ABC lethargy factor.	Transformed ABC stereotype factor
Difficult child score on PSI.	Pearson Correlation	.561**	.702**	1.000	.858**	.654**	.490**	.357*
	Sig. (2-tailed)	.000	.000	.	.000	.000	.001	.015
	N	46	46	46	46	46	46	46
Total score on PSI.	Pearson Correlation	.863**	.865**	.858**	1.000	.527**	.496**	.262
	Sig. (2-tailed)	.000	.000	.000	.	.000	.000	.078
	N	46	46	46	46	46	46	46
Transformed ABC irritability factor	Pearson Correlation	.276	.502**	.654**	.527**	1.000	.573**	.425**
	Sig. (2-tailed)	.063	.000	.000	.000	.	.000	.003
	N	46	46	46	46	46	46	46
Transformed ABC lethargy factor.	Pearson Correlation	.316*	.524**	.490**	.496**	.573**	1.000	.389**
	Sig. (2-tailed)	.033	.000	.001	.000	.000	.	.008
	N	46	46	46	46	46	46	46
Transformed ABC stereotype factor	Pearson Correlation	.071	.310*	.357*	.262	.425**	.389**	1.000
	Sig. (2-tailed)	.638	.036	.015	.078	.003	.008	.
	N	46	46	46	46	46	46	46
ABC hyperactivity factor	Pearson Correlation	.357*	.476**	.570**	.528**	.740**	.615**	.566**
	Sig. (2-tailed)	.015	.001	.000	.000	.000	.000	.000
	N	46	46	46	46	46	46	46
ABC inappropriate speech factor.	Pearson Correlation	.306*	.369*	.371*	.394**	.347*	.140	.386**
	Sig. (2-tailed)	.039	.012	.011	.007	.018	.352	.008
	N	46	46	46	46	46	46	46
Total score on ABC.	Pearson Correlation	.394**	.592**	.669**	.619**	.825**	.716**	.655**
	Sig. (2-tailed)	.007	.000	.000	.000	.000	.000	.000
	N	46	46	46	46	46	46	46

### Correlations

		ABC hyperactivity factor	ABC inappropriate speech factor.	Total score on ABC.
Transformed HBCL score for professionals named as most helpful.	Pearson Correlation Sig. (2-tailed) N	.237 .112 46	.077 .613 46	.245 .101 46
Transformed HBCL score for professionals named as least helpful.	Pearson Correlation Sig. (2-tailed) N	.017 .919 39	.046 .781 39	.018 .915 39
Age of the individual completing the questionnaire.	Pearson Correlation Sig. (2-tailed) N	.319* .031 46	.213 .156 46	.224 .134 46
Is at least one member of the family in employment?	Pearson Correlation Sig. (2-tailed) N	.269 .071 46	.274 .065 46	.295* .046 46
Marital status	Pearson Correlation Sig. (2-tailed) N	-.120 .425 46	-.269 .071 46	-.039 .795 46
Child's age	Pearson Correlation Sig. (2-tailed) N	-.179 .235 46	.007 .961 46	-.128 .397 46
Child's gender	Pearson Correlation Sig. (2-tailed) N	-.495** .000 46	-.254 .089 46	-.556** .000 46
Matched most helpful professional's BLAME score	Pearson Correlation Sig. (2-tailed) N	.116 .522 33	.481** .005 33	.078 .665 33

### Correlations

		ABC hyperactivity factor	ABC inappropriate speech factor.	Total score on ABC.
Matched most helpful professional's INFORM score	Pearson Correlation Sig. (2-tailed) N	.060 .739 33	.070 .697 33	.091 .614 33
Matched most helpful professional's VALIDATE score	Pearson Correlation Sig. (2-tailed) N	.101 .575 33	.128 .479 33	.059 .744 33
Matched most helpful professional's INSTRUCT score	Pearson Correlation Sig. (2-tailed) N	.016 .929 33	-.215 .229 33	-.007 .968 33
Matched Least helpful professional's BLAME score	Pearson Correlation Sig. (2-tailed) N	-.284 .346 13	-.335 .263 13	-.254 .402 13
Matched Least helpful professional's INFORM score	Pearson Correlation Sig. (2-tailed) N	.013 .965 13	.170 .579 13	.173 .573 13
Matched Least helpful professiona's VALIDATE score	Pearson Correlation Sig. (2-tailed) N	-.201 .511 13	-.131 .669 13	-.162 .596 13
Matched Least helpful professionals INSTRUCT score	Pearson Correlation Sig. (2-tailed) N	-.016 .959 13	.137 .655 13	-.055 .859 13
Is contact ongoing with the most helpful professional?	Pearson Correlation Sig. (2-tailed) N	-.116 .445 46	-.166 .269 46	-.164 .276 46
Is contact ongoing with the least helpful professional?	Pearson Correlation Sig. (2-tailed) N	-.047 .771 41	-.069 .667 41	-.049 .760 41



### Correlations

		ABC hyperactivity factor	ABC inappropriate speech factor.	Total score on ABC.
Number of contacts with most helpful professional.	Pearson Correlation Sig. (2-tailed) N	-.023 .881 45	.043 .779 45	-.068 .658 45
Number of contacts with least helpful professional.	Pearson Correlation Sig. (2-tailed) N	-.196 .231 39	-.235 .150 39	-.283 .081 39
Length of contact with most helpful professional in months.	Pearson Correlation Sig. (2-tailed) N	-.079 .616 43	-.145 .352 43	-.162 .298 43
Length of contact with least helpful professional in months.	Pearson Correlation Sig. (2-tailed) N	-.063 .712 37	-.071 .674 37	.004 .980 37
Parent's understanding of most helpful professional role.	Pearson Correlation Sig. (2-tailed) N	.330* .025 46	.238 .111 46	.371* .011 46
Parent's understanding of least helpful professional role.	Pearson Correlation Sig. (2-tailed) N	.211 .191 40	-.045 .785 40	.184 .257 40
Parents' beliefs about parents on the blame factor.	Pearson Correlation Sig. (2-tailed) N	-.146 .334 46	-.123 .415 46	-.123 .414 46
Parents' beliefs about parents on the inform factor: transformed.	Pearson Correlation Sig. (2-tailed) N	-.030 .841 46	-.103 .495 46	-.087 .564 46
Parents' beliefs about parents on the validate factor.	Pearson Correlation Sig. (2-tailed) N	-.138 .361 46	.046 .759 46	-.166 .271 46

### Correlations

		ABC hyperactivity factor	ABC inappropriate speech factor.	Total score on ABC.
Parents' beliefs about parents on the instruct factor: transformed.	Pearson Correlation Sig. (2-tailed) N	-.163 .278 46	-.150 .318 46	-.223 .137 46
Partner/spouse helpfulness on FSS.	Pearson Correlation Sig. (2-tailed) N	-.255 .091 45	-.290 .053 45	-.134 .379 45
Informal kinship support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.276 .066 45	-.178 .241 45	-.250 .098 45
Formal kinship support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.463** .001 45	-.293 .051 45	-.416** .004 45
Social organisations support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.220 .147 45	-.121 .427 45	-.199 .190 45
Professional services support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.065 .669 45	-.062 .687 45	.000 .998 45
Total support on FSS.	Pearson Correlation Sig. (2-tailed) N	-.344* .021 45	-.254 .093 45	-.269 .074 45
Parent distress score on PSI.	Pearson Correlation Sig. (2-tailed) N	.357* .015 46	.306* .039 46	.394** .007 46
Parent - child dysfunctional interaction score on PSI.	Pearson Correlation Sig. (2-tailed) N	.476** .001 46	.369* .012 46	.592** .000 46

### Correlations

		ABC hyperactivity factor	ABC inappropriate speech factor.	Total score on ABC.
Difficult child score on PSI.	Pearson Correlation	.570**	.371*	.669**
	Sig. (2-tailed)	.000	.011	.000
	N	46	46	46
Total score on PSI.	Pearson Correlation	.528**	.394**	.619**
	Sig. (2-tailed)	.000	.007	.000
	N	46	46	46
Transformed ABC irritability factor	Pearson Correlation	.740**	.347*	.825**
	Sig. (2-tailed)	.000	.018	.000
	N	46	46	46
Transformed ABC lethargy factor.	Pearson Correlation	.615**	.140	.716**
	Sig. (2-tailed)	.000	.352	.000
	N	46	46	46
Transformed ABC stereotype factor	Pearson Correlation	.566**	.386**	.655**
	Sig. (2-tailed)	.000	.008	.000
	N	46	46	46
ABC hyperactivity factor	Pearson Correlation	1.000	.463**	.933**
	Sig. (2-tailed)	.	.001	.000
	N	46	46	46
ABC inappropriate speech factor.	Pearson Correlation	.463**	1.000	.520**
	Sig. (2-tailed)	.001	.	.000
	N	46	46	46
Total score on ABC.	Pearson Correlation	.933**	.520**	1.000
	Sig. (2-tailed)	.000	.000	.
	N	46	46	46

\*. Correlation is significant at the 0.05 level (2-tailed).

\*\*. Correlation is significant at the 0.01 level (2-tailed).